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ACQUIRED IMMUNE DEFICIENCY SYNDROME: AN EVALUATION OF THE FEDERAL ROLE

HEARING

BEFORE A

SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

Special Hearing

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CONTENTS

	Page
Statement of Michael Zimmerman, Senior Associate Director, General Accounting Office	2
Prepared statement	7
Statement of Cindy Basetta, General Accounting Office	2
Statement of E. Charlton Prather, M.D., MPH, State health officer, Department of Health and Rehabilitative Services	18
Prepared statement of Gregory L. Coler, secretary, Florida Department of Health and Rehabilitative Services	19
Statement of Lois Frankel, State representative, Florida Legislature, chairperson, House task force on AIDS	27
Statement of Margaret Fischl, M.D., medical director, Comprehensive AIDS Program and AIDS Clinical Research Unit, University of Miami, Jackson Memorial Hospital Medical Center	29
Prepared statement	30
Statement of David G. Droller, M.D., Broward General	29
Prepared statement	33
Statement of James T. Howell, M.D., director, Palm Beach County Health Department	29
Prepared statement	34
Statement of Wade Parks, M.D., medical virologist, Division of Immunology and Infectious Diseases, Department of Pediatrics, University of Miami School of Medicine	49
Prepared statement	59
Statement of Gwendolyn B. Scott, M.D., associate professor of pediatrics, Division of Infectious Disease and Immunology, University of Miami School of Medicine	49
Prepared statement	62
Statement of Carl Eisdorfer, Ph.D., M.D., professor and chairman, University of Miami Department of Psychiatry; director, Biopsychosocial Center for the Study of AIDS	49
Prepared statement	69
Statement of Sally Dodds, ACSH, executive director, Health Crisis Network, Inc	78
Prepared statement	84
Statement of Father Fred Tondalo, P.S.J., executive director, Center One, Anyone in Distress, Inc	78
Prepared statement	88
Statement of Louis Max, LCSW, project director, Comprehensive AIDS Program of Palm Beach County, Inc	78
Prepared statement	90
Statement of Linda S. Quick, executive director, Health Council of South Florida, Inc	78
Prepared statement	94
Letter from Senator Lawton Chiles	106
Letter from Robert Kunst, director, Cure AIDS Now	106

Page

Narrative request for proposal identifying need and outreach/monthly schedule ... 108
Cure AIDS Now—The Miami project ... 111
Dade County memorandum on Meals-on-Wheels Program ... 114
Memoranda from Robert P. Kunst ... 115
Letter from G.N. Khlyabich, vice minisiter, chief State sanitary doctor of the U.S.S.R ... 117
Articles:
Lifeline for AIDS victims—"Meals on wheels" helps the hungry and lonely ... 119
It's time for an AIDS 'Manhattan project' ... 121
Smallpox vaccine 'triggered AIDS virus' ... 123
Doctors urge education on AIDS to curb spread among minorities ... 125

ACQUIRED IMMUNE DEFICIENCY SYNDROME: AN EVALUATION OF THE FEDERAL ROLE

WEDNESDAY, AUGUST 12, 1987

U.S. SENATE,
SUBCOMMITTEE ON LABOR, ,HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
West Palm Beach, FL.

The subcommittee met at 9:42 a.m., in the chambers of the Palm Beach County Commissioners, West Palm Beach, FL, Hon. Lawton Chiles (chairman) presiding.

Present: Senator Chiles.

NONDEPARTMENTAL WITNESSES

Senator CHILES. Good morning. I am happy to be in West Palm Beach and I want to thank Carol Roberts, the chairman of the county commissioners, and Mr. Jan Winters, the county administrator, for their generosity in allowing us to use these facilities.

Next month, as chairman of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, I must recommend to the Senate what we should spend on AIDS in the fiscal year that starts next October 1, just 1½ months away. The purpose of this hearing is to gain your advice on the need for Federal AIDS funding, to learn both how much we need to spend and also what the AIDS spending priorities should be.

As chairman of both the subcommittee charged with the health appropriations and of the Budget Committee, I am particularly aware of the challenge posed by the AIDS epidemic. In 1980, AIDS was unknown. Today we know it as a lethal infectious disease without a cure of vaccine. The AIDS infection may lie dormant for many years, but it may also be passed to others during this dormant period. The chilling prospect of this disease spreading throughout the population makes AIDS the No. 1 health threat in the country today.

The Federal Government, especially the Congress, has recognized and responded to this threat. In 1982, the AIDS research budget was $5.5 million. By 1987, we were investing $447 million, and the 1988 proposal for the Public Health Services agencies is $791 million. As a matter of fact, it is largely because of earlier federally funded research

that we have the people, the equipment and scientific sophistication to learn so much about this new disease so quickly.

Florida ranks third in the Nation for the number of AIDS cases, and nearly 75 percent of our cases are in three counties: Dade, Broward, and Palm Beach.

Here in Florida, the most recent figures show that 2,600 cases have been reported and that there are AIDS cases in 45 of our 67 counties in the State. Our State has been disproportionately hit by the AIDS epidemic, and 120 new cases are reported each month.

The Florida public health response to AIDS is among the best in the Nation. I believe a lot can be learned from the several panels of Florida experts that have agreed to testify this morning.

Nationally, we estimate there are 1.5 million people with the infection; 39,263 with the full-blown disease; and 22,548 people have died in the United States of the disease to date.

We certainly need to find a cure and an effective vaccine, but that may be years away. In the meantime, we need to improve treatment procedures for AIDS patients and certainly educate the public to halt the spread of the disease.

At my request, the General Accounting Office [GAO] has undertaken and completed its first study of the Federal AIDS effort. This report is being released at the hearing this morning. Mr. Zimmerman of the GAO will summarize that report for us.

This morning we will also hear testimony from Florida health officials, scientists, physicians, support groups, interest groups, and community organizers. We are pleased to have a representative of Secretary Coler, Dr. Prather of the Florida State Health Department, also here to give us an overview of the AIDS situation in Florida.

In the course of combating AIDS in our State, the people and organizations that we will hear from today have learned a great deal. One thing I have learned in Washington is that our Florida scientists, physicians and public health officials are at the cutting edge. I certainly look forward to your advice this morning.

STATEMENT OF MICHAEL ZIMMERMAN, SENIOR ASSOCIATE DIRECTOR, GENERAL ACCOUNTING OFFICE

ACCOMPANIED BY CINDY BASETTA

Senator CHILES. Our first witness this morning is Michael Zimmerman, Senior Associate Director of the General Accounting Office. With him is Ms. Cindy Basetta, and I understand that she's done a lot of work on this report. We welcome you to the subcommittee and ask you to proceed with your testimony.

Mr. ZIMMERMAN. Thank you very much.

We are pleased to be here today to discuss the report we are issuing to you and presenting the views of experts on the adequacy of the administration's proposed fiscal year 1988 budget for AIDS prevention activities.

Of the proposed budget about two-thirds would be spent on research to find a vaccine and a cure, and about one-third or $247 million, for prevention and education activities.

Since development of the vaccine is at least 5 years away and probably much longer, Federal, State, and local health department officials and experts in our research community agree that education and prevention activities are the most powerful tools available to reduce the potential impact of the AIDS epidemic.

Overall, the experts we interviewed concurred with the priorities reflected in the administration's AIDS prevention budget which are limiting the spread of AIDS among intravenous [IV] drug users, targeting education at high risk groups and at the general public, and expanding voluntary counseling and testing. The experts did not, however, agree with the proposed funding levels and one or more of them suggested increases of at least $50 million for treatment of intravenous drug users, $250 million for expanded capacity at voluntary testing and counseling centers, and $65 million for educational campaigns.

I should add that these estimates were made without regard to competing health priorities or Federal budgetary constraints.

The experts cited the sharing of contaminated needles by IV drug users as a dangerous and alarming problem because it represents the primary means of spreading the AIDS virus among the heterosexual population.

Nationwide, 60 percent of heterosexual cases and 73 percent of cases in newborns were transmitted as a result of IV drug use.

Senator CHILES. 60 percent——

Mr. ZIMMERMAN. That's correct.

Senator CHILES [continuing]. In adults is it now?

Mr. ZIMMERMAN. That's correct.

Senator CHILES. Heterosexuals?

Mr. ZIMMERMAN. Heterosexual adults.

Senator CHILES. And 73 percent of the, of the infants?

Mr. ZIMMERMAN. That's correct, infant infection.

Senator CHILES. Comes from infectious needles?

Mr. ZIMMERMAN. That's correct, from IV drug users——

Senator CHILES. That's contaminated——

Mr. ZIMMERMAN [continuing]. That are infected.

The experts believe that methadone treatment can reduce the spread of AIDS by reducing the number of addicts who inject heroin. Public health officials in New York suggested an additional $50 to $150 million to expand methadone treatment in New York City, where about one-third of the Nation's IV drug users live. Officials in Boston and San Francisco also indicated that they needed additional Federal funds to expand methadone treatment.

Any barriers preclude expansion of drug treatment programs and other means aimed at IV drug users. For example, communities often resist expansion of methadone clinics in their neighborhoods. While drug treatment may be the preferred option, rapid expansion over the

next few years will be expensive. In the interim, less costly but also controversial methods of reducing the spread of AIDS such as teaching drug users how to disinfect needles can be implemented.

The experts told us that the AIDS education for high-risk groups and the general population should be pursued with a sense of urgency and a level of funding that is appropriate for a life or death situation. Moreover, to limit the spread of AIDS infection, education must be expanded immediately in all geographic areas including those where there are still a few cases.

According to the experts, the administration's budget request of $155 million does not provide sufficient funding for education of the general public and targeted groups. Some experts suggested at least $100 million—in contrast to the $29 million in the budget request—is needed to launch a massive public education campaign on how AIDS is spread. They suggested using paid commercial advertising instead of relying on public service announcements, which are generally not aired during prime viewing hours. American Medical Association officials suggested increasing funding for AIDS education to at least $65 to $215 million more than the budget request.

Many experts expect the Federal Government to underwrite a major portion of the funding for educational AIDS efforts. We believe, however, that the private organizations, such as health and life insurance companies, have strong financial incentives to become involved in AIDS educational efforts because they will also have large expenses in the next few years if the AIDS epidemic goes unchecked.

The populations at risk of contracting AIDS number nearly 10 million persons. At an average cost of $45 per person, potential resources for these individuals requesting tests would approach $450 million. Assuming the States matched the administration's budget amount of $90 million, about $250 million more in total funding would be needed to meet this demand.

However, experts we contacted were unable to predict the potential demand for testing from either high-risk individuals or the general public. Morever, intensive educational campaigns may increase demand for testing in relatively low-risk populations. Precise budgetary needs, therefore, are very difficult to estimate.

Your office also asked that we discuss the cost of caring for AIDS patients.

Recently, the Rand Corp., predicted that medical treatment costs for AIDS patients from 1986 to 1991 might reach $38 million by 1991. The study is based on projections on new research indicating that the future caseload may be greater than the Public Health Service originally predicted.

This study probably understates the total cost of treatment because it excludes the costs of services received outside the hospital such as outpatient, drug, and community support services. In fact, despite widespread concern about the financial repercussions of AIDS, data on the costs for medical care of a person with AIDS are surprisingly scarce.

Furthermore, no estimates are available of the costs associated with AIDS-related complex—known as ARC—Which can be debilitating, even fatal.

Other factors, however, may raise or lower total costs. First, the distribution of cases of AIDS and ARC by diagnosis may change over time. For example, the proportion of AIDS patients with certain cancers may decrease while severe lung infections may increase. Since the latter is more expensive to treat, direct personal medical costs will be expected to rise. Other changes in case-mix may also raise or lower total treatment costs.

Second, numerous drugs are being tested and are under development. These drugs may prolong life but require different health care services, which may in turn raise or lower costs. Moreover, drugs like AZT may improve the quality of life and decrease productivity losses if AIDS patients can continue to work longer than would have been possible without the drug.

A review of cases—cost studies done between 1985 and 1987 show that meaningful cost comparisons are difficult to make because the studies varied in their definitions of AIDS, the types of costs included, the time periods analyzed, and geographic areas.

Estimates of lifetime hospital costs range from $24,500 to $147,000. The variation is due largely to differences in lengths of hospital stays for AIDS treatment, for which there is no standard medical model. There is evidence that hospital lengths of stay have declined in some cities. AIDS patients are now less likely to be admitted to intensive care units than they were when less was known about the disease.

Also, the average length of stay is shorter areas where alternatives to hospitalization exist, such as out-patient diagnosis and therapy at home and community-based services. Providers in Florida have been able to cut hospital costs by setting up out-patient treatment services for AIDS patients. I understand other witnesses this morning will discuss this in more detail.

While it may be possible to increase home and community-based services in other communities where the caseloads are comprised of mostly homosexual men, it is more problematic in areas where IV drug users account for a greater percentage of the cases.

In summary, although it is difficult to predict how the costs of treating AIDS may change over time, there is evidence that the costs per case could be minimized by delivering care outside the hospital setting. This appears to be occurring in several areas around the country including south Florida.

This concludes my statement. I will be more than glad to answer the questions you may have.

PREPARED STATEMENT

Senator CHILES. Thank you, Mr. Zimmerman.

We will place your statement in the record at this point and then move on to some questions.

[The statement follows:]

STATEMENT OF MICHAEL ZIMMERMAN

Summary

As of June 1987, nearly 38,000 AIDS cases had been reported to the Centers for Disease Control (CDC), up from about 300 in 1981. In 1981, the federal budget included $200,000 for the Centers for Disease Control to study AIDS. For fiscal year 1988, the proposed federal Public Health Service budget had increased to more than $790 million, with about one-third ($247 million) for prevention activities.

Since researchers believe a vaccine will probably not be available for general use in the near future, federal, state, and local health department officials and other experts agree that prevention activities, such as education and voluntary counseling and testing, are the most powerful tools available to reduce the potential impact of the AIDS epidemic. GAO obtained the views of over 20 experts from the research and health professional communities, advocacy groups, and state and local health departments in New York, California, Florida, Massachusetts, Illinois, and Washington, D.C., on the adequacy of the funding levels and appropriateness of the funding priorities in the administration's AIDS prevention budget.

Overall, the experts GAO interviewed generally concurred with the priorities reflected in the administration's AIDS prevention budget but suggested that the proposed budget be increased by at least

-- $50 million for methadone treatment to contain the spread of the AIDS virus among intravenous drug users,

-- $65 million for educational campaigns targeted at high-risk groups and the general population, and

-- $250 million for expanded capacity at voluntary testing and counseling centers.

These estimates reflect the views of the experts, not GAO, and were made without regard to competing health priorities or federal budgetary constraints. GAO identified some options that could minimize the need for increased federal funding.

Investing in prevention now could help contain the costs of AIDS. Treating AIDS victims may, according to CDC, cost $8.5 billion in 1991. Including productivity losses associated with deaths of persons in their prime working years, the total social costs of AIDS may reach $64 billion in 1991. A recent estimate of the total costs of treating AIDS predicted that cumulative medical treatment costs might reach $38 billion by 1991. Estimates of lifetime hospital costs ranged from $24,500 to $147,000. Most of the current studies on the costs of AIDS probably understate the total costs of treatment because they exclude the costs of services received outside the hospital, such as drugs, hospice care, and community volunteer support services.

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss issues related to federal efforts to limit the spread of Acquired Immunodeficiency Syndrome, commonly known as AIDS. My comments will primarily relate to a

report[1] we are issuing to you today on the adequacy of the administration's proposed fiscal year 1988 funding levels for AIDS prevention activities in the U.S. Public Health Service (PHS). I will also discuss the cost of caring for AIDS patients and the possible implications of alternative treatments on those costs.

My comments are based on our review of the literature and the views of over 20 experts from the research and health professional communities, advocacy groups, and state and local health departments in New York, California, Florida, Massachusetts, Illinois, and Washington, D.C. While the experts generally concurred with the prevention priorities as reflected in the budget, they told us that additional funds were needed for education, testing, and counseling services. These views are those of the individuals we contacted and not necessarily those of their affiliated organizations.

Growth in AIDS Cases and Federal Expenditures

As of June 1987, nearly 38,000 AIDS cases had been reported to the Centers for Disease Control (CDC), up from about 300 in 1981. Most of the cases were clustered in high-incidence areas, such as New York City, San Francisco, Los Angeles, Miami, and Houston. The Public Health Service predicts that there will be a total of 270,000 cases by 1991. While San Francisco and New York currently account for over half the cases, by 1991 eighty percent of the cases are predicted to be in other areas.

The Public Health Service's budget for AIDS prevention and research has increased from $200,000 in fiscal year 1981 to over $790 million proposed by the administration for fiscal year 1988. Of this budget, about two-thirds ($519 million) would be spent on biomedical research to find a vaccine and cure, and one-third ($247 million) for prevention and education activities. The budget request also includes $24 million for maintaining the safety of the blood supply and other activities.

Experts' Views on the Fiscal Year 1988 Budget

Since development of a vaccine is at least 5 years away and probably longer, federal, state, and local health department officials and experts in the research community agree that

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[1] AIDS Prevention: Views on the Administration's Fiscal Year 1988 Budget Proposals. (GAO/HRD-87-126BR, August 12, 1987).

and prevention activities are the most powerful tools to reduce the potential impact of the AIDS epidemic.

the experts we interviewed concurred with the priorities in the Administration's AIDS prevention budget for fiscal --limiting the spread of AIDS among intravenous drug rgeting education at high-risk groups and at the general n, and expanding voluntary counseling and testing. ts did not, however, agree with the proposed funding 155 million for education ($55 million targeted at IV drug d $92 million for testing and counseling ($15 million at IV drug users). One or more of the experts suggested administration's proposed budget be increased by at least

.llion for treatment of intravenous drug users,

nillion for expanded capacity at voluntary testing and eling centers, and

llion for educational campaigns.

timates reflect the views of the experts and were made regard to competing health priorities or federal budgetary nts. Although GAO did not develop its own funding dations, we offer comments that may reduce the need for cost increases suggested by the experts.

the Spread of AIDS in Intravenous Drug Users

rts cited the sharing of contaminated hypodermic needles by ous drug users as a dangerous and alarming problem because sents the primary means of spreading the AIDS virus among rosexual population. Nationwide, 60 percent of xual cases and 73 percent of cases in newborns were ted as a result of intravenous drug use.

e treatment can, the experts believe, reduce the spread of reducing the number of addicts who inject heroin. Public fficials in New York suggested an additional $50 to $150 to expand methadone treatment in New York City, where about l of the nation's IV drug users live. Officials in Boston Francisco also indicated that they need additional federal expand methadone treatment, but did not cite a dollar

Many social, political, and financial barriers preclude expansion of drug treatment programs and other means aimed at intravenous drug users. For example, communities often resist expansion of methadone clinics in their neighborhoods. While drug treatment may be the preferred option, rapid expansion over the next few years will be expensive. In the interim, less costly but also controversial methods of reducing the spread of AIDS that do not involve changing drug users' basic behavior, such as teaching drug users how to disinfect needles, can be implemented.

Educating the Public About AIDS

The experts told us that AIDS education for high-risk groups and the general population should be pursued with a sense of urgency and a level of funding that is appropriate for a life-or-death situation. Moreover, to limit the spread of AIDS infection, education must start or be expanded immediately in all geographic areas, including those where there are as yet few cases. In particular, because the virus can be spread through unprotected heterosexual intercourse, the experts believe that clear and direct messages about safer sexual practices, such as using condoms, can help prevent the spread of AIDS in the general public.

According to the experts we contacted, the administration's budget request of $155 million does not provide sufficient funding for education of the general public and targeted groups. Experts from the Institute of Medicine's (IOM) Committee on a National Strategy for AIDS estimated that at least $100 million--in contrast to the $29 million in the budget request--is needed to launch a massive public education campaign on how AIDS is spread. They suggested that the Centers for Disease Control use paid commercial advertising in prime viewing hours instead of relying on public service announcements, which are generally not aired during prime viewing hours. American Medical Association (AMA) experts suggested increasing funding for AIDS education by 3 to 5 times over the fiscal year 1987 spending level--$65 to $215 million more than the fiscal year 1988 budget request.

Many experts expect the federal government to underwrite a major portion of funding for educational AIDS efforts. We believe, however, that private sector organizations, such as insurance companies, have strong financial incentives to become involved in AIDS educational efforts because they will also have large outlays in the next few years if the AIDS epidemic goes unchecked.

Also, the costs of the mass media campaign envisioned by the Institute of Medicine may be reduced if television and radio stations were encouraged to broadcast public service announcements during prime viewing hours as an alternative to paid advertising. Other relatively inexpensive measures, such as posting notices on public transportation, would provide a constant reminder of the threat of AIDS.

Providing Testing and Counseling Services

The experts expressed concern that individuals requesting testing and counseling typically had to wait several weeks to be tested. Citing unacceptable waiting periods at test sites in Chicago, for instance, the AMA recommended that testing capacity be increased by 3 to 5 times.

The populations at high risk of contracting AIDS, such as homosexual/bisexual men, IV drug users, and their sexual partners, number nearly 10 million persons, according to recent CDC estimates. At an average cost of $45 per person, potential resources needed if these individuals request testing would approach $450 million. Assuming equal shares of federal and state resources of about $184 million, over $250 million more in funding would be needed to meet this demand.

Experts we contacted at CDC and IOM were unable to predict, however, the potential demand for testing from either high-risk individuals or the general public. Additional costs also would be incurred for heterosexuals who perceived themselves to be at risk for whatever reason; persons who received multiple blood transfusions in high-incidence areas before 1985; and prostitutes. Moreover, intensive educational campaigns may increase demand for testing in relatively low-risk populations. Precise budgetary needs are, therefore, difficult to estimate.

The Total Costs of Treating AIDS

Investing in prevention now can help contain the future direct medical costs of treating AIDS. A study prepared for the Centers for Disease Control projected that treating AIDS may cost $8.5 billion in 1991 (or 1.4 percent of total personal health expenditures, up from 0.2 percent in 1985). Including the indirect costs of losses in productivity associated with premature death, these researchers predicted the total social costs of AIDS may

reach $64 billion by 1991.[2] A more recent estimate of the total costs of treating AIDS predicted that cumulative medical treatment costs might reach $38 billion by 1991.[3] This study based its projections on recent research indicating that the future caseload may be greater than the Public Health Service originally predicted.

These studies probably understate the total costs of treatment because they exclude the costs of services received outside the hospital, such as drugs, institutional or home-based long-term care, hospice care, ambulatory physician and ancillary services, and community support services. In fact, despite widespread concern about the financial repercussions of AIDS on the health care system, data on the costs for medical care of persons with AIDS are surprisingly scarce. Furthermore, no estimates are available of the costs associated with AIDS-related complex--AIDS-virus infections that do not meet the CDC definition of AIDS.

Other factors, however, may raise or lower total costs. First, the distribution of cases of AIDS and AIDS-related complex by diagnosis may change over time. For example, according to CDC, the proportion of AIDS patients with certain cancers, such as Kaposi's sarcoma, may decrease while severe lung infections, such as pneumocystis carinii pneumonia, may increase. Since the latter is more expensive to treat, direct personal medical costs would be expected to rise. Other changes in case-mix may also raise or lower total treatment costs.

Second, numerous drugs are being tested and are under development. Drugs like AZT (azidothymidine) affect treatment costs in two ways--by raising pharmaceutical costs and by changing the clinical course of the disease. Patients on this drug may live longer but require different health care services, which may in turn raise or lower costs. Moreover, drugs like AZT may improve the quality of life and decrease productivity losses if AIDS patients can continue to work longer than would have been possible without the drug. Obviously, development of a cure or vaccine will change the cost situation.

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[2]Scitovsky, Anne and Dorothy Rice. "Estimates of the Direct and Indirect Costs of Acquired Immunodeficiency Syndrome In The United States, 1985, 1986, and 1991," Public Health Reports, Vol. 102, No. 1, Jan.-Feb. 1987, pp. 5-16.

[3]Pascal, Anthony. The Costs of Treating AIDS Under Medicaid, 1986-1991. Rand Corporation, Santa Monica, Calif. May 1987.

Costs Per Case of Treating AIDS

A review of cost studies done between 1985 and 1987 shows that the costs per case of treating AIDS vary significantly.[4] Meaningful cost comparisons are difficult, however, because the studies varied in their definitions of AIDS, the types of costs included, the time periods analyzed, and the geographic areas. The studies were conducted using data from New York, California, Florida, Massachusetts, Maryland, Minnesota, Alabama, and New Mexico.

Estimates of lifetime hospital costs ranged from $24,500 to $147,000. The variation is due largely to differences in lengths of hospital stays for AIDS treatment, for which there is no standard medical model. There is also some evidence suggesting that AIDS patients are now less likely to be admitted to intensive care units than they were when less was known about the disease. According to two recent articles in the Journal of the American Medical Association,[5] the use of inpatient hospital treatment for AIDS appears to have decreased over time. As a result, lifetime treatment costs for AIDS patients seem to have fallen. Specifically, days in the hospital from diagnosis to death fell from 168 for the first 10,000 cases[6] to 35 days (based on San Francisco data) and to 62 days (based on Massachusetts data) in 1984 and 1985.

The average length of stay is also shorter in areas where alternatives to hospitalization exist, such as outpatient diagnosis and therapy and home- and community-based services. In San Francisco, the mean length of hospital stay for all AIDS diagnoses was 11.7 days in 1984. Voluntary organizations in San Francisco provide support services to AIDS patients that allow them to leave the hospital sooner or avoid hospitalization completely. Providers in Florida also have been able to cut hospital costs by setting up

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[4]Sisk, Jane. "The Costs of AIDS: A Review of the Estimates." Health Affairs, Vol. 6, No. 2, Summer 1987, pp. 5-21.

[5]Scitovsky, Anne, Mary Cline, and Philip Lee. "Medical Care Cost of Patients With AIDS in San Francisco," Journal of The American Medical Association, Vol. 256, No. 22, Dec. 12, 1986, pp. 3103-3106, and George Seage, et al, "Medical Care Costs of AIDS in Massachusetts," Journal of The American Medical Association, Vol. 256, No. 22, Dec. 12, 1986, pp. 3107-3109.

[6]Hardy, Ann et al. "The Economic Impact of the First 10,000 Cases of Acquired Immunodeficiency Syndrome in the United States." Journal of The American Medical Association, Vol. 255, No. 2, 1986, pp. 209-215.

outpatient treatment services for AIDS patients. Other witnesses will discuss these efforts in more detail.

While it may be possible to increase home-based services in other communities where the caseloads are comprised of mostly homosexual men, it is more problematic in areas where intravenous drug users account for a greater percent of cases. For example, the average length of stay for AIDS patients in New York City was 50 days in 1984. This may reflect, in addition to differences in severity of illness, a lack of outpatient or home-based care for AIDS patients in New York City, of whom 30 percent are intravenous drug users.

In summary, although it is difficult to predict how the costs of treating AIDS may change over time, there is evidence that the costs per case can be minimized by delivering care outside the hospital setting. This appears to be occurring in several areas of the country.

This concludes my statement. I will be happy to answer any questions you may have.

Senator CHILES. You noted that treatment for IV drug users was the very first priority for additional Federal funding among those you interviewed. And my understanding is that boils down to where we were talking about two things, education for money for IV drug users and then the use of methadone.

Mr. ZIMMERMAN. That is correct, sir.

Senator CHILES. Do we have any—were you able to compile any information or is there any way of being able to measure whether increased funding for methadone, how much success we can have with that?

I can remember a few years back when we were worried about the heroin epidemic, we attempted to try to go to methadone treatment or some of it was used and it didn't seem to have been that successful at the time.

Mr. ZIMMERMAN. Basically they're talking about methadone being used as a substitute, not for getting people to change the drug habit, but to go away from using the needle. So the experts we talked to were of the belief that in that instance methadone would probably be more successful than serving as a cure for IV drug use. In essence, they want to use it as a substitute for IV injection.

Senator CHILES. So in effect, rather than try to cure the addict here, they're talking about just trying to get them to substitute methadone for heroin?

Mr. ZIMMERMAN. That is correct.

Senator CHILES. Again, is there any kind of empirical evidence out there to show the kind of success rate or whether that can have any kind of success?

Mr. ZIMMERMAN. I'm not aware, maybe Ms. Basetta can answer that.

Ms. BASETTA. They're looking at that issue now in New York. And there are several articles that are in press that are being prepared by Mr. John Dejolei (phonetic) and Samuel Friedman.

I'm not sure what the results of the article are. They're generally finding that there is some responsiveness in the IV drug community to the threat of AIDS but at least so far, at the level of effectiveness of training and education in that population, isn't as effective as it's been in the homosexual population. But it's more effective than people thought it would be.

Senator CHILES. Well, my concern is here we're talking about big dollars for going to methadone in heavy drug use areas in New York and California and those areas. I don't know that we know what that will produce for us. And that's why I wonder, you know, about putting big additional dollars in that before we have some kind of test or some kind of way to be sure.

We know if we can get these people to use sterilized needles, even if they were going to, you know, continue their use of heroin, they would be so much better off. And certainly because of that, I know we are in a dilemna of trying to provide sterilized needles to heroin addicts. No one is going to exactly want to see us do that or have us do that. But I

just wonder if education isn't still the area here that we could have the highest payoff in and do we know whether—obviously we're not being very effective in the education that we have put out there today. How are we talking about trying to target the education now to these addicts and trying to see that they get the message?

As you say, it seems that the homosexual community has responded much better.

Mr. ZIMMERMAN. In our discussions with the people in New York, it's kind of a localized thing, they have to put people out on the street that will interact with the IV drug users and their friends and so on. It's not something that you can just do in a media campaign. It takes people walking the street and interacting directly with these people which is somewhat expensive. And they feel that that is some——

Senator CHILES. It couldn't be as expensive as putting them all on methadone though.

Mr. ZIMMERMAN. Probably not.

Senator CHILES. Yes.

Mr. ZIMMERMAN. Probably not. Because the cheapest option is the sterilized needle approach and as you've indicated that has its elements of controversy surrounding it as well.

Senator CHILES. Did you find that the agenda and priorities of the Department of Health and Human Services were in line with those recommended by the public health experts and researchers that you interviewed?

Mr. ZIMMERMAN. Yes; we did.

As I pointed out in testimony and in the report, curbing the spread of heterosexual transmitted AIDS was a top priority. And for that reason HHS is putting funds toward the IV drug users. There is also agreement on the need for more education and targeting homosexual, bisexual men, school age children, and health care workers, as well as certain minorities in inner-city areas. So it seems to us that, that basically the experts that we talked to were reasonably comfortable with the focus of the administration's budget and feel that they have the right priorities.

Senator CHILES. Does it appear that we, are we being too general in our education focus now? In other words, we're trying to cover the whole area or should we have that general coverage and then have a much stronger coverage directed at the target population?

How is that——

Mr. ZIMMERMAN. I think that the latter is probably the way to go, a general education program that would be directed at the bulk of the population and then selected campaigns in high-risk groups of people, probably localized in nature, would be the most appropriate way to go. At least that's the impression that I got. Maybe Ms. Basetta can add to that.

Ms. BASETTA. No; I would agree with that.

One thing that I would add is——

Senator CHILES. Pull your mike over closer, if you would.

Ms. BASETTA [continuing]. Foreign countries, especially European countries that currently have much lower caseloads than we have at this point, have begun much earlier in their, in the stages of their epidemics to educate their general population, not just their high-risk groups. And they've invested quite a bit in a fairly intensive media campaign to educate the general public.

Senator CHILES. Well, we recently included $20 million in the supplemental for a mass mailing to go out. That would be to the general population. But what you're saying is that some of the other foreign countries spent proportionately considerably more in going to their general population?

Ms. BASETTA. I'm not certain of the exact dollar amount that they have spent. I just know that their media campaigns have been fairly intensive. They——

Senator CHILES. Intensive media campaigns, much more intensive than what we have had?

Ms. BASETTA. Right, much more intensive. For example, they have had a mass mailing in England, and they have also had numerous public ads on public transportation. For instance, they have a cancellation stamp there that says, "AIDS, don't die of ignorance," that goes out on a fair number of all the letters in the country.

Senator CHILES. Did the government pay for this time on the air?

Mr. ZIMMERMAN. I think most of it is done on government-owned networks, as I recall. So I think it's basically the government's paying for the time.

Senator CHILES. Considering the Federal Government budgetary crisis, that we don't have unlimited dollars, how can we mitigate the cost of proposals made by experts in your report?

Mr. ZIMMERMAN. Well, in our report we make note of some options that we think exist. For example, we expect that the insurance companies, the health and life insurance companies are going to start getting very involved in educating the public on AIDS, simply it's that they're at high risk like everybody else in terms of financial loss. Also, we believe that more use of public announcements during prime time might be a way of cutting down on the education, on the cost of educating. We point out in our report the option of sterile needle approach seems to us to be less costly than the use of methadone. And there are others in the report, I think, that do highlight some options that are available, though I must add we did not explore every possible option in the timeframe we had that would mitigate or cut back on the cost estimates.

Senator CHILES. Did any of the experts suggest that we should not provide expanded funding for testing and counseling until there was more complete confidentiality and not discrimination legislation that took place?

Mr. ZIMMERMAN. That question was not—that issue was not raised in our discussions with the experts.

Senator CHILES. Well, I want to thank the General Accounting Office and you all for your very quick response with your report. It's your first report, I'm sure that we're going to have you making a followup report on this.

Mr. ZIMMERMAN. Thank you very much.

Ms. BASETTA. Thank you.

Senator CHILES. Thank you very much.

STATEMENT OF E. CHARLTON PRATHER, M.D., MPH, STATE HEALTH OFFICER, DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

Senator CHILES. Our next witness is Dr. Carlton Prather, the State health officer.

Florida, with 2,700 cases of AIDS ranks third among the States in the AIDS incident rate. Our profile of cases differs somewhat from the national averages. We have the second largest number of children with AIDS nationally, while 4 percent of those cases are transmitted heterosexually, 15 percent of the cases in Florida are transmitted heterosexually.

Dr. Prather is going to give us an overview of the AIDS situation in the State of Florida.

And I understand you have Dr. Witte with you this morning.

Dr. PRATHER. Yes; he is here, Senator Chiles.

Senator CHILES. Well, we'd be glad to have him come up here with you too.

Dr. PRATHER. Dr. Witte?

Senator CHILES. He is director of our Florida AIDS office.

Dr. PRATHER. Yes; he is.

Senator CHILES. Dr. Prather, Dr. Witte, we're delighted to have you all with us.

Dr. PRATHER. We're complimented to be invited, Senator Chiles. I've come to apologize for Secretary Coler, whose business of state caused significant change in his obligations and I was complimented that he would invite us to come in his stead. But I extend his apologies for not being here. We do thank you for the privilege of being here.

Senator CHILES. Yes, sir, thank you.

Dr. PRATHER. And we thank you for holding these hearings in Florida because as you remarked, we're third in the Nation and we think we should have at least one-third of the resources.

That's an aside, that's not in my prepared remarks.

Secretary Coler did prepare a statement for the record and for your attention, may I present it to you?

PREPARED STATEMENT

Senator CHILES. Yes, sir; your statement in full will be included in the record, and if you can brief that for us, we'll be happy to have time to ask questions.

[The statement follows:]

STATEMENT OF GREGORY L. COLER, SECRETARY, FLORIDA DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

THE PROBLEM

Florida has consistently ranked third in the nation in the cumulative number of reported cases of Acquired Immune Deficiency Syndrome (AIDS). The United States cumulative case count in late July 1987, was 38,000. Florida cumulative cases of the disease number 2,700 or approximately 7% of the nationwide count.

The Department of Health and Rehabilitative Services has maintained good surveillance of the epidemic in Florida since 1981. Projections made by the State Health Office in February 1987, show that the Florida cumulative case count will continue to double approximately every twelve months. Florida expects a total of 4,000 cumulative cases of AIDS by July 1988, 8,000 cases by 1989, 16,000 cases by 1990, and 32,000 cumulative cases of the disease by 1991.

These grim projections cannot be averted. The virus that causes AIDS is slow to claim its host. Persons infected with the human immunodeficiency virus may show no signs or symptoms of illness for 3, 5, 7 even 10 years or more. Consequently, most persons in Florida and the nation who will be diagnosed with AIDS between now and 1991 are already infected with the virus.

Persons diagnosed with AIDS represent only a fraction of the problems associated with the epidemic. The Centers for Disease Control (CDC) in Atlanta estimate that there is from 2 to 10 persons who suffer from a lesser illness, AIDS-related complex (ARC), for every diagnosed case of full-blown AIDS. Florida may have as many as 26,000 persons currently suffering from ARC.

The Centers for Disease Control (CDC) also estimates that an even larger number of persons are infected with the virus that causes AIDS and show no signs or symptoms of illness. CDC estimates that 50 human immunodeficiency virus (HIV) infections exist for each reported case of AIDS. In Florida, that translates to more than 130,000 persons infected as of today.

Seventy-five percent of the Florida cases have been reported from the southeastern counties of Palm Beach, Broward, Dade, and Monroe. Nevertheless, we do consider AIDS to be a statewide problem. Forty-five of Florida's 67 counties have reported one or more cases of AIDS. Projections by our staff show that all counties in Florida will likely have reported one or more cases of AIDS within the next 12 to 18 months.

National data show that the AIDS epidemic has disproportionately affected minorities. Twenty-five percent of the cases reported nationally are black persons and 14% are hispanic persons. In Florida, the corresponding percentages are 36% black and 14% hispanic.

Florida differs in other significant ways from the national averages. Four percent of the nationwide cases have been reported as heterosexual persons. Fifteen percent of the reported cases in Florida are heterosexual persons. Eleven of the 15% of heterosexual cases in Florida are among persons who have immigrated to the state from Central Africa or the Caribbean where heterosexual transmission of the virus is thought to have been occuring for several years.

Other numbers are also grim! Florida has reported the second greatest cumulative number of cases of AIDS among

children. Like other states, approximately 80% of the children with AIDS in Florida were born to mothers who were infected with the human immunodeficiency virus.

In summary, AIDS cases in Florida have been reported from a broad cross-section of the population. Homosexual and bisexual males, intravenous drug users, heterosexuals, and children are casualties of the epidemic in Florida.

THE FLORIDA RESPONSE

The Florida response to the AIDS epidemic has been in 6 major areas: 1) surveillance, 2) counseling/testing, 3) health education/risk reduction, 4) patient care, 5) special studies, and 6) services for residential clients. Let me briefly comment on each of these areas.

1. **Surveillance** - Reporting of AIDS cases in Florida has been ongoing since the beginning of the epidemic in 1981. A formal AIDS surveillance program was established through the State Health Office in 1983. AIDS case reports completed by physicians, hospitals, and laboratories are routed through the county health departments to the State Health Office in Tallahassee. A Florida AIDS Case Registry is maintained in Tallahassee with provisions for confidentiality and security of the files. Statistical data from the case registry are distributed to more than 600 persons each month. Florida case reports, without names, are provided bi-weekly to the Centers for Disease Control in Atlanta for the national AIDS case registry.

   Surveillance data are useful in tracking spread of the epidemic in Florida, targeting special education programs to high incidence areas, and allocation of state and federal resources to areas with the greatest need.

2. **Counseling and Testing** - Florida was one of the first states in 1985 to establish anonymous (alternate) testing sites after the Food and Drug Administration licensed the first antibody test for the virus that causes AIDS. Twenty-five counseling and testing sites were established in June 1985 in the 16 counties reporting the greatest number of AIDS cases. Anonymous testing sites were added in three additional counties in 1987.

   Anonymous counseling and testing means that persons may present themselves at one of the sites without giving a name or name identifier. Pre- and post-test counseling are the most important components of the services. More than 21,000 persons have voluntarily been counseled and tested since the anonymous program was established two years ago. More than 3,000 persons or 14% of the number had positive HIV antibody tests.

   Confidential and informed consent human immunodeficiency virus antibody counseling and testing services are now being added to selected clinics in all 67 county health departments. Persons at risk for exposure to the virus that causes AIDS are encouraged to voluntarily avail themselves of the services. Written consent of the client is required prior to testing.

3. **Health Education/Risk Reduction** - The State Health Office and county health departments distribute thousands of pamphlets and brochures weekly to persons at risk for AIDS,

health care workers, community groups, and others. The department provides a toll-free hotline for state residents. The number is 1-800-FLA-AIDS. More than 1,200 persons per month call the hotline for information, counseling, and referral inquiries.

The State Health Office and health departments in Palm Beach, Broward, Dade, and Monroe counties are beginning the second year of a special federally funded five-year health education/risk reduction project. Extensive efforts are in progress in these high incidence counties to break the cycle of infection.

4. **Patient Care** - The 1986 Florida Legislature appropriated special funds to establish a model AIDS patient care network in Dade County through a contract between Jackson Memorial Regional Medical Center and the Department of Health and Rehabilitative Services. More than 42% of AIDS cases in the state have been reported from Dade County.

   The Dade County Network is designed to provide a continuum of quality health care services to persons with AIDS and AIDS-related complex at a minimum cost. Approximately 700 persons have been served by the Dade County Network in the first 10 months of operation.

   Similar AIDS patient care networks are being established with state general revenue funds in 11 other counties where more than 90% of the Florida AIDS cases have been reported. The state has assumed a major role in providing patient care services to persons with AIDS and ARC.

5. **Special Studies** - The Department of Health and Rehabilitative Services frequently collaborates with the Centers for Disease Control to complete AIDS related studies in Florida. A special study was completed in Belle Glade, Florida, in 1986. Data from the study show that the human immunodeficiency virus is transmitted from one person to another in Belle Glade by the same routes that the virus is transmitted in other communities. Specifically, there was no data to suggest that mosquitoes transmit the virus that causes AIDS.

   The Department and the CDC are completing the second year of a two year study of prostitutes in Miami. Preliminary results of the study show that approximately 18% of the prostitutes participating in the study have been exposed to the human immunodeficiency virus. These results have serious implications for heterosexual spread of the virus in Florida.

6. **Department Clients in Residential Facilities** - On any given day, approximately 9,500 persons reside in facilities operated by the Florida Department of Health and Rehabilitative Services. These facilities range from large institutions for the mentally ill or developmentally disabled to secure detention centers and training schools for delinquent youths. These clients are the responsibility of the department. Our staff is examining the full range of AIDS-related issues that impact on these clients. Services for clients with AIDS, ARC, and HIV-infection are being strengthened with careful attention to the rights of the individual client and confidentiality of medical records.

FUTURE NEEDS

The Florida response to the AIDS epidemic has been substantial. State general revenue appropriations have grown from approximately $500,000 the 1985-86 state fiscal year, to $7.5 million the 1986-87 fiscal year, to about $13.5 million the current fiscal year. Approximately 60% of the current state appropriations are dedicated to patient care services.

Federal dollars flowing into Florida for public health services have also increased sharply. The current annual level of federal funds is approximately $2,000,000. The amount is expected to grow to more than $3,000,000 per year within the next 12 months. These dollars have been invaluable in the Florida effort!

More federal dollars are urgently needed! There is no vaccine to prevent infection by the human immunodeficiency virus nor cure for a person with AIDS. Education is the only weapon to fight the epidemic. Florida needs millions of dollars for massive public information and education campaigns targeted at persons at risk for infection.

Florida also needs additional federal funds to expand and strengthen existing counseling and testing services for persons at risk for AIDS. Testing and counseling services are crucial. One-on-one counseling of persons at risk for infection is very labor intensive and, therfore, very costly.

Finally, federally funded surveillance programs and special studies need to be strengthened and expanded. We must continue to thoroughly track spread of the disease in order to gauge and target our reponses. The heterogeneous and rapidly increasing population in Florida creates an ongoing need for special studies related to AIDS. Knowledge gained in Florida will be a major part of the national effort to control the epidemic.

CONCLUSION

Thank you for the opportunity to provide this testimony. Together, the state and federal government can conquer the AIDS epidemic.

'RATHER. Thank you, sir.
he record I am E. Charlton Prather, MP, MPH, the director of
te Health Office, functioning as the State health officer and
ily called the deputy assistant secretary for health in Florida.
for the record as I was instructed to do.
, Florida has, since we began to collect this statistic, ranked third
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ida differs in other significant ways from the national averages.
percent of the nationwide cases have been reported as hetero-
persons. In Florida that figure is 15 percent.

Senator CHILES. Why do you think that's a high figure?

Dr. PRATHER. It's very difficult to—I can only speculate.

I don't want to think that we have more prostitutes. We do believe that prostitution is in some way involved with the heterosexual spread. We do have a significant number of drug abusing-type cases and we've—our data suggests that much of our heterosexual spread comes from needle-sharing bisexual males through the female route. Those two things are our speculation as to the possibilities of why.

Senator CHILES. I have seen some figures on the infection in prostitutes in Florida, in Miami, and the other cities. It's very, very high, the carriers that we have.

Dr. PRATHER. There are some special studies between us and the CDC of prostitutes in Miami where we're running at 18-percent positivity rate for AIDS.

Senator CHILES. So when we're talking about education for people, that's something that they ought to be aware of.

Dr. PRATHER. It's a tough group to get to. We need motivational education, yes, we do, and we'll come to that.

How do we do it?

Well, additionally, among our heterosexual cases, significant numbers of our cases in Florida are folks who have immigrated to Florida from Haiti or other areas of the Caribbean and indeed from central Africa where the heterosexual spread is thought to play a prominant part of the epidemiology of AIDS.

Other numbers are also grim, Senator. Florida has reported the second greatest cumulative number of cases of AIDS among children. Like other States, approximately 80 percent of the children with AIDS in Florida were born to mothers who were infected with the virus.

Senator CHILES. Do we have any breakdown of those cases or are those drug, IV drug users or do we know what——

Dr. PRATHER. We believe that significant numbers are. We do have hard data that suggests that.

Very good, Dr. Scott is one of your subsequent speakers who is our lead pediatrician for AIDS in Florida. She should be able to provide some finite numbers.

Senator CHILES. Fine, sir.

Dr. PRATHER. Dr. Scott, I hope that's OK.

Well, our Florida response has been in six major areas, surveillance, trying to keep up with what's going on, where and when; counseling and testing; health education, public information, risk reduction; patient care; a series of special studies and services for residential clients. I'd like to briefly overview those.

In surveillance, reporting of AIDS cases in Florida has been ongoing since the syndrome was identified. A formal AIDS surveillance program was established through our State health office in 1983. Case reports completed by physicians, hospitals, and laboratories are routed through county health departments to the State health office in Tallahassee. A Florida AIDS case registry is maintained in Tallahassee with provisions

for confidentiality and for security of the files. Statistical data from the case registry are distributed to more than 600 persons each month. Florida case reports, without names, are provided every other week to the Centers for Disease Control in Atlanta for the national AIDS case registry.

Such data are useful in tracking spread of the epidemic in Florida——

Senator CHILES. Doctor, if you could brief a little of that for me as you go along it would help me a little bit in our time that we would have, if you would.

Dr. PRATHER. Run quicker, thank you, OK, I can do that.

Our counseling and testing, very quickly, we are proud of the fact that we're one of the first States to apply for and obtain Federal dollars to establish alternate test sites. Those have been ongoing, and we presently have 25 alternate test sites operative in Florida. It's notable that some 22,000 folks have been tested in there with a positivity rate of that self-selected group of some 14 percent.

Our health education and risk reduction programming has been through the public media, through pamphlets and special printed materials for specific population groups. A statewide AIDS information number, our AIDS hotline, and we like the number, it's an 800 number, Florida AIDS, we receive some 1,200 calls a month for our information about AIDS through that.

Our patient care programming is done through networks, the most notable of which at the moment is the south Florida AIDS network, the Dade County network, designed to provide a continuum of quality health care services to persons with AIDS and ARC at a minimum cost. Some 700 persons have been served through this system during the first 10 months of operation.

Senator CHILES. What has the cost of that been, do you know?

Dr. PRATHER. You also have a Mrs. Linda Quick who administers that. She can give finite numbers, if I may defer the question.

I mentioned one of our special studies, that of the prevalence of AIDS in prostitutes in Miami, that the other notable special studies funded by the CDC and our legislation for special attention to the problems in Belle Glade.

Senator CHILES. CDC is the Centers for Disease Control?

Dr. PRATHER. Yes; it is.

Senator CHILES. OK.

Dr. PRATHER. I apologize, sir.

Presently we are giving very special attention to the some 9,500 persons that are in a Florida health rehabilatative services institution on any particular day. The disease AIDS and infections with the AIDS virus are being seen more and more in our institutions. A major effort presently is underway for the development of—for lack of a better term—a statewide policy given to our concern and attention to those folks who are committed into our care and are housed in one of our institutions.

For the future, to very quickly hit that, the cost has been substantial. Florida response to our legislature has been substantial with $13.5 million from our State legislature this year with some 60 percent of that going uniquely to patient care services. Comparably Federal dollars have been useful to us and we anticipate $3 million this coming year. We clearly need more.

The problem of public education and more importantly identification of particular pieces of the Florida public with motivational information is the critical item. We think that's costly, you've addressed—a previous speaker addressed the cost of the one-to-one contact with the folks' potential for methadone. Clearly to get at the high-risk groups in Florida it does—shall require a innovative approach, one how to provide information, but more importantly how to motivate, to take action on that information.

And in a nutshell, Senator Chiles, that is our Florida picture and we thank you sincerely for the opportunity to be present.

Details of our report have been provided to your staff.

Senator CHILES. Dr. Prather, we've heard testimony from the GAO that in the future, 80 percent of the new AIDS cases will be in other than high incidence areas. For Florida that would mean you would start seeing more cases outside of the Dade, Broward, and Palm Beach areas.

If that, in fact, happens, are we ready in Florida to meet that challenge?

Dr. PRATHER. We are standing on the threshold. We're not really ready to meet that challenge. We believe that the first line of defense, again, is education and motivation, counseling, and testing. We use those words in that order, counseling, testing. Counseling is more important than the testing. One who identifies as a high-risk group, who identifies himself as high risk, it's more important that he understand the epidemiology of AIDS and what he can do or she can do to protect herself and her significant others than it is for the testing. Counseling is one-to-one, very labor intensive and very expensive. We do not have those counselors, Senator, poised at every county line waiting.

Senator CHILES. Is there a State policy on AIDS that is in place now?

Dr. PRATHER. Not in the formal sense. I'm aware that our Florida house has appointed an interim committee that's giving attention to the matter of a State policy for AIDS. Our department is giving very special attention to a statement of the public policy. We're trying to develop a paper at the moment for public consumption and legislative consumption aimed at approaching a clear sense of direction and a statement of the public policy as regards to AIDS. That is in the developmental stages on several fronts.

Senator CHILES. We have heard about the reluctance of many physicians and dentists to treat AIDS patients.

What can the State do to try to help overcome this problem?

Dr. PRATHER. It was my pleasure last night to participate in the organizing meeting of an AIDS task force appointed by the president of the Florida Medical Association [FMA] as a member of the group.

The first item of the agenda, the FMA, the president of the AIDS task force, is how to educate, how to inform Florida physicians and Florida dentists such that they will willingly treat and manage and care for AIDS patients.

Not an immediate answer, Senator, but I believe through the efforts of the legislature presently, through indeed Florida's expansion of its Medicaid eligilibity criteria, with a significant increase in fee systems in Florida, through Medicaid coupled with supported effort on the part of the Florida Medical Association, I'm optimistic that answers are forthcoming.

Senator CHILES. Tell me a little more about the Florida AIDS budget. You mentioned the State's funding totaled $13.5 million with 60 percent devoted to patient case services.

What are the other major areas of funding and do you expect the patient care services to continue to be the first priority?

Dr. PRATHER. I do expect the patient care services to continue to be the first priority.

The other portions of those dollars go to testing and counseling, to the surveillance system with about $1.5 million for public education and information. Those are the broad categories.

Senator CHILES. How do you see the role breaking down between the responsibility of the State and the Federal Government in this regard?

The Federal Government, of course, is more involved in the overall task of trying to find a vaccine, trying to find a cure, funding much of the research grants and moneys that are going out in that regard. The States are going to have to have more responsibility here, are they not, of the actual treatment?

Dr. PRATHER. Yes; I think the funding pattern in Florida has fairly well established that pattern already in which our patient care has become a prominent piece. Some $7.5 million of our $13 million appropriation for this year is geared for patient care.

In the sense of our divided role, through the Medicaid system, probably through the Medicare system and purely through the Social Security Act, I think the Federal Government should continue to provide those mechanisms. We recognize that partnership through those Federal dollars for the overall problem.

I personally would like to see the Federal Government take on considerably more than the initiative for public education and motivation.

Senator CHILES. Doctor, we thank you and the doctor very much for your testimony and your work in that regard.

Dr. PRATHER. It's a compliment to be here, Senator, thank you, sir.

Senator CHILES. Thank you.

STATEMENT OF LOIS FRANKEL, STATE REPRESENTATIVE, FLORIDA LEGISLATURE, CHAIRPERSON, HOUSE TASK FORCE ON AIDS

Senator CHILES. I notice that we do have Lois Frankel here. She is in the Florida Legislature and the chairperson, I understand, of the AIDS task force.

Lois, I wonder if we could get you to come up a minute and tell us something about what your task force is doing. I know I've surprised you a little bit with saying we were going to call on you but——

Ms. FRANKEL. Thank you, Senator. And I appreciate you being here, having this hearing today.

I am the representative from district 83 here in Palm Beach County and am the chairperson of our House task force on AIDS which consists of a number of about 11 numbers of our health care committee. And we have been charged by our speaker to study the AIDS issues and will be touching upon many of the areas that you're hearing discussion on today and, in fact, will be having our own fact-finding hearing in Miami in early September.

We will be looking at a number of the issues such as education in Florida, the effect AIDS will have on the insurance industry are people getting insurance, the discrimination issues that you mentioned, the confidentiality and voluntary and mandatory testing issues.

And we are finding that there's almost, it seems to be no end to the number of areas of our lives that are being touched by AIDS.

I have met with a number of the people you are going to be speaking with this morning. I have found them most informative.

One issue that I see that you will not be addressing today, but in light of the facts of your position I think it's important to consider the overall economic impact that AIDS is going to have not only here in Florida but in the country. Because that, as you can tell from the figures already, not only is it going to cost us billions and billions of dollars to take care of AIDS patients, we're talking about a disease that's striking really the most productive members of our society, those between the ages of 20 and 50 years of age. And we know that in Florida 1 out of 9 men between the ages of 30 and 40 is now infected, at least it's thought to be that they're infected with the AIDS virus so we'll be losing from our economic work force productive members of society, those who we would hope would be not only producing but paying income tax. So we're going to see billions of dollars of loss from our economy, not only a drain from our health care system, but in terms of productivity and pay to make America work.

So I think that's an angle that you all need to consider because I think that you'll find is that this is truly a problem that the more resources and money that you spend to fight it, the more to fight this disease, the more that we will end up saving for this country in the long run.

But let me let you get on to these other more knowledgeable people, and thank you again on behalf of the people of south Florida and Florida for your interest and your good work in this area.

Senator CHILES. Well, we thank you very much for what you're doing here. We look forward to seeing what your panel accomplishes here——

Ms. FRANKEL. Thank you.

Senator CHILES [continuing]. What your study group comes up with as well. We look forward to continuing to work with you in this regard.

Ms. FRANKEL. Thank you.

STATEMENTS OF:

MARGARET FISCHL, M.D., MEDICAL DIRECTOR, COMPREHENSIVE AIDS PROGRAM AND AIDS CLINICAL RESEARCH UNIT, UNIVERSITY OF MIAMI, JACKSON MEMORIAL HOSPITAL MEDICAL CENTER

DAVID G. DROLLER, M.D., BROWARD GENERAL

JAMES T. HOWELL, M.D., DIRECTOR, PALM BEACH COUNTY HEALTH DEPARTMENT

Senator CHILES. Our next series of witnesses are physicians who have special experience in the treatment of AIDS patients. We have Dr. Margaret Fischl from Jackson Memorial Hospital, University of Miami. Dr. Fischl is a director of the AIDS Out-Patient Clinic at Jackson Memorial and director of the NIH sponsored AIDS treatment evaluation unit at Jackson Memorial.

Dr. Droller is well known in Broward County for his expertise in the treatment of AIDS patients.

Dr. Jim Howell is director of the Palm Beach County Health Department, the unit which treats the largest percentage of AIDS patients in Palm Beach County.

PREPARED STATEMENTS

We are happy to have each of you here. I'd like to request that each of you please summarize your statements and we'll put your whole statement in the record and it'll give us a little more time for questions and Dr. Fischl, we'll start with you.

[The statements follow:]

STATEMENT OF MARGARET FISCHL

As the Medical Director of the Comprehensive AIDS Program and AIDS Clinical Research Unit at the University of Miami/Jackson Memorial Hospital Medical Center, I would like to thank you for this opportunity to testify, and I would like to share with you our experiences in caring for patients with AIDS, focusing mainly in the areas of patient care, clinical research and training and education.

As you may be aware, Florida reports the third to fourth largest number of cases of AIDS in the nation, and Miami reports the fifth largest number of cases per SMSA (Standard Metropolitan Statistical Area). Our medical center serves not only as a primary health care center for more than half of the patients with AIDS reported in the state of Florida, but also serves as a tertiary referral center for difficult cases of medical diagnosis and management. It is also a major research center for the development of new drugs and therapies.

The care and treatment responsibilities impacting on our center, as with many similar centers around the country, is not infrequently overwhelming. To date, we have seen and cared for more than 1,200 patients with AIDS and over 500 patients with AIDS-related illnesses. We have screened over 5,000 individuals for HIV infections and over 1,000 potential candidates for research protocols. By the end of 1985, we were seeing approximately 40 to 45 new patients with AIDS or AIDS-related illnesses per month and had scheduled over 2,000 clinic appointments in our outpatient or research clinics. Our average inpatient service climbed to 40 to 45 patients with AIDS at any one time. The average length of hospital stay ranged from 14 to 36 days, and the average cost for health care delivery for a single patient over a two year period was close to $125,000.

Based on projected increases in the incidence of AIDS, we estimate that by 1989 more than 50 percent of our resources in medicine would have to be directed to the treatment and care of patients with AIDS and AIDS-related illnesses.

Based on this experience and increasing projections by the Centers of Disease Control, we implemented several programs in 1986 in the hopes of decompressing our medical center and focusing on the development and implementation of alternative or novel ways of caring for patients with AIDS and AIDS-related illnesses. Through the assistance of funding by HRSA (Health Resources and Services Administration of the Public Health Services), the Robert Wood Johnson Foundation, and the State of Florida, we have been able to build an ambulatory and day treatment center and expand critical community resources. Since its opening, we are continuing to develop a comprehensive outpatient ambulatory program and day treatment center, utilizing frequent outpatient clinic visits, and treatment in an outpatient or home setting. We are in the process of building a dedicated inpatient unit which should be functional by the end of this year. In the interim, a temporary unit is being developed within the medical services.

These facilities and programs have allowed us to decrease the need for and length of hospital stays, to treat patients in an outpatient setting or home care infusion programs, and to seek assistance from community hospitals and physicians in sharing the burden of health care delivery. To date, we are seeing approximately 60 new patients with AIDS or AIDS-related illness per month and expect over 7,000 appointments to be made in our outpatient and research clinics. Our average inpatient census for AIDS patients has fallen to 15 to 25 patients at one time, despite an increasing incidence of AIDS. The

average length of hospital stay has decreased to 7 to 14 days, and the average cost to deliver medical care per patient in this setting over a 2 year projected period should be decreased by a factor of 50 to 75%.

In implementing this program, we have focused additionally on new and novel ways of diagnosing and treating life-threatening infections frequently seen among patients with AIDS. These types of programs should not only further improve medical care delivery and decrease health care costs at our own center, but should be able to be implemented in other facilities. For example, to make a diagnosis of Pneumocystis carinii pneumonia, the most common infection seen among patients with AIDS, a lung biopsy is needed. Currently, sputum can be induced through a simple procedure by aerosoling a salt solution. This sputum can then be sent to the appropriate Pathology laboratory for a rapid diagnosis of Pneumocystis. If this procedure is followed correctly, approximately 65% to 85% of patients with Pneumocystis pneumonia can be diagnosed with this simple method. This procedure cannot only decrease the need for lung biopsy but can also be used in an outpatient setting for early recognition and diagnosis of certain pneumonias. It has become increasingly accepted that early recognition and intervention with antibiotic therapy will not only improve outcome for patients with AIDS but will further decrease the need for lengthy hospital stays. Finally, with an outpatient treatment center, we have also been able to discharge patients early from the hospital to continue treatment in an outpatient setting, either in the treatment center or through home infusion programs. The continued support of such programs and support for their wider implementation will be critical for the health delivery system in order to meet the demands that will be placed on it over the next several years. Longterm, however, alternative ways of funding these programs will need to be developed.

In part, the success of this program and similar programs throughout the country has relied heavily on returning some of the responsibilities of primary health care back to community hospitals and physicians. To facilitate this process, we have established a network of community physicians interested in developing treatment programs for AIDS patients at their local hospitals or offices. We have included an educational program to update this working group on the latest information about AIDS, to discuss diagnosis and difficult patient management, and to expand our treatment and research programs to include their patients. More recently, we have undertaken the development of an educational program to a network of primary care physicians and facilities throughout Miami and Dade county area. The continued success of such treatment programs will depend heavily on continuing technical assistance by academic medical centers to primary care providers, development of broad range community step-down services, and availability of universal funding for patient care. The primary care systems, including both physicians and hospitals, cannot be expected to provide uncompensated indigent care.

Our medical center, along with many other centers, has also had to develop unique experience of evaluating and treating patients from broad social and ethnic backgrounds. Along with several other academic medical centers, we have continued to see a dramatic increase in the incidence of AIDS among intravenous drug abuser and heterosexuals. Many of those individuals are from an inner city indigent population and frequently involve minority groups. It will, therefore, be essential that health care delivery programs and services be made available to community physicians and facilities servicing these areas and patients.

As a major clinical research center, we also test agents to combat the AIDS virus, such as AZT, new drugs for the treatment of Kaposi's sarcoma, the cancer associated with AIDS, and new antibiotics to treat the various

infections associated with AIDS. Most of our research program is carried out within the confines of a clinical research unit which has allowed us to see a large number of patients in an intensive program. To accommodate the growing demands of treatment research, we have expanded our research program on at least 3 occasions. Presently, I have a staff of over 35 individuals working in the clinical research unit and have implemented over 15 different studies evaluating various drugs in the treatment of AIDS and AIDS-related illnesses. Through funding from the Centers of Disease Control, the NIH intramural programs, and to some extent private health related industries, we have been able to rapidly develop a large research program in a relatively short period of time. Funding which pays the direct costs associated with these research projects are important, but are not sufficient for the development of comprehensive AIDS research programs or centers. Growth in AIDS and AIDS-related research within an academic medical center has strained the system beyond its capacity to provide for institutional resources, space, capital equipment, and administrative support. In addition, the hidden efforts involved with national coordination and planning of programs have not been compensated. Furthermore, the approach to research in AIDS is frequently multidisciplinary, involving both adult and pediatric medicine, immunology, pharmacology, virology, neurology and psychiatry. Means to coordinate and network these various components to further maximize the clinical research effort is desperately needed. It has become clear that the development of comprehensive AIDS research centers are now mandatory and federal funds are urgently needed to fund these centers.

Finally, the academic medical center with frequent affiliations with institutions of higher education, maintains interest in a wide variety of educational issues. It has become apparent in the expansion of our treatment, care and research programs in AIDS, that a physician manpower shortage will occur. It is also likely that a personnel shortage may occur more widely within many areas of both patient care and research. Many individuals that would be attracted into research programs or treatment programs for AIDS have already been recruited. With the ever demanding expansion of treatment and research programs, the need for more physician manpower will only increase. Training and educational programs for the development of graduate and undergraduate medical personnel will therefore be essential. Furthermore, with the expansion of AIDS programs outside of major medical centers, the need for continuing medical education for community based physicians and health care workers is crucial. Finally, with the extensive research programs already in place, release of new and updated information occurs every day. Mechanisms for effectively and quickly translating new information to both health care professionals and the public is also urgently needed.

In summary, it is clear that many new alternatives and novel programs addressing patient care, research and educational issues have gotten off the ground, but continued expansion and increasing support will be desperately needed over the next several years.

I would like to thank you again for this opportunity to provide this testimony and would be happy to answer any questions which you may have.

STATEMENT OF DAVID G. DROLLER

THANK YOU FOR PROVIDING ME THE OPPORTUNITY OF TESTIFYING AT THIS COMMITTEE HEARING.

I AM A PHYSICIAN IN BROWARD COUNTY PRESENTLY IN THE PRIVATE PRACTICE OF INFECTIOUS DISEASES, A SUBSPECIALTY OF INTERNAL MEDICINE. I HAVE BEEN CARING FOR PATIENTS WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) SINCE THE RECOGNITION OF THIS NEW ILLNESS IN BROWARD COUNTY IN 1979.

SINCE 1980 THE NUMBER OF PATIENTS SATISFYING THE CENTER OF DISEASE CONTROL CASE DEFINITION OF AIDS HAS RISEN DRAMATICALLY IN BROWARD COUNTY. FOR EXAMPLE, OVER THE LAST TWO YEARS, THE NUMBER OF NEWLY DIAGNOSED CASES OF AIDS AT A PARTICULAR TAX-SUBSIDIZED MEDICAL CENTER IN BROWARD COUNTY HAS RISEN FROM 75 PER YEAR IN 1985 AND 1986 TO 50 FOR THE FIRST 4 MONTHS OF 1987, WITH THE NUMBER CONTINUING TO RISE UNABATINGLY. THE NUMBER OF PEOPLE HOSPITALIZED AT THIS PARTICULAR INSTITUTION WITH AIDS AT ANY ONE TIME HAS BEEN 15 TO 20, AT A CONSERVATIVE COST OF $500 TO $1000 PER DAY PER PERSON. THESE NUMBERS DO NOT INCLUDE THOSE INFECTED WITH THE HUMAN IMMUNODEFIENCY VIRUS(HIV), YET NOT SATISFYING THE CASE DEFINITION OF AIDS. PRESENTLY 40% TO 60% OF MY OFFICE PRACTICE IS INVOLVED IN THE CARE OF THOSE WITH AIDS AND COMPLICATION OF HIV INFECTION.

MOST OF THESE VICTIMS ARE EITHER INDIGENT, UNDERINSURED OR SHORTLY WILL BE UNINSURED WITH REGARD TO MEDICAL EXPENSES. MANY ARE DISCHARGED FROM THEIR JOBS, OR ARE TOO ILL TO RETURN TO WORK, AND THEREFORE UNABLE TO ASSUME PAYMENT OF HEALTH INSURANCE PREMIUMS. AS A CONSEQUENCE, TO THE ENORMOUS PSYCHOLOGIC TRAUMA OF KNOWING THEY HAVE A LETHAL ILLNESS IS ADDED THE ADDITIONAL ONUS OF TRYING TO OBTAIN AND PAY FOR MEDICAL CARE AND BASIC SUBSISTENCE.

BASED ON A PROJECTED NUMBER OF PATIENTS WITH AIDS IN BROWARD COUNTY OF APPROXIMATELY 4000 BY 1990, AND ASSUMING AT LEAST 50% WILL BE UNABLE TO AFFORD MEDICAL CARE, WE CAN ANTICIPATE CONSERVATIVELY 1500-2000 PATIENTS WITH AIDS NEEDING CARE IN AN OUTPATIENT AMBULATORY SETTING. THESE PROJECTED NUMBERS DO NOT INCLUDE THOSE WHO ARE ASYMPTOMATIC OR HAVE OTHER COMPLICATIONS OF HIV INFECTION WHICH DO NOT MEET THE CDC DEFINITION OF AIDS. THE TOTAL MAY BE 50 TIMES THE NUMBER PROJECTED WITH AIDS. THESE NUMBERS ALSO DO NOT REFLECT

INCREASED LIFE EXPECTANCY, AS NEWER MODALITIES OF TREATMENT ARE DISCOVERED AND DEVELOPED.

IN ANTICIPATION OF THE RISING NUMBER OF PEOPLE WITH AIDS AND HIV-ASSOCIATED ILLNESS, THE BROWARD COUNTY PUBLIC HEALTH UNIT, UNDER THE DIRECTION OF DR. CHARLES KONIGSBERG, HAS INITIATED THE DEVELOPMENT OF AN OUTPATIENT AMBULATORY FACILITY TO HELP DEAL WITH THE MANY MEDICAL AND SOCIAL PROBLEMS ENCOUNTERED BY THOSE WITH HIV INFECTION.

THIS CLINIC IS BEING STAFFED BY PRIVATE PRACTIONERS FROM BROWARD COUNTY WHO HAVE HAD EXPERIENCE IN DEALING WITH THE MANY MEDICAL COMPLICATIONS OF AIDS, AND WHO HAVE VOLUNTEERED THEIR TIME FROM THEIR PRIVATE PRACTICES. IT IS ANTICIPATED THAT THIS OUTPATIENT FACILITY CAN SERVE AS THE HUB OF A NETWORK ALONG WITH THE VARIOUS TAX-SUBSIDIZED HOSPITALS, TO SERVE THE COMPLEX MEDICAL AND SOCIAL NEEDS OF THOSE WITH HIV INFECTION.

AS CAN BE APPRECIATED, THE COSTS INVOLVED WILL BE ENORMOUS. IT IS HOPED THAT WITH THE HELP OF COUNTY, STATE AND FEDERAL FUNDING, CARE FOR THE VICTIMS OF THIS DEVASTATING ILLNESS IN BROWARD COUNTY CAN BE PROVIDED IN A HUMANE, YET COST-EFFECTIVE MANNER.

THANK YOU FOR YOUR KIND ATTENTION.

STATEMENT OF JAMES T. HOWELL

Thank you for the opportunity to briefly review the AIDS treatment, medical and social programs in Palm Beach County.

First, let me state that in early July Palm Beach County officially counted its 300th victim of this disease. The HIV (Human Immunodeficiency Virus) has infected thousands of our citizens; many more are suffering related diseases with this virus than meet the official CDC AIDS definition. This is truly a tragic new public health epidemic of the 1980's that will unfortunately take a heavy toll on the health, economic and social service sectors of our county.

The Palm Beach County Health Department is part of the Florida Department of Health and Rehabilitative Services and is operated by contract with the Palm Beach County Board of County Commission.

Palm Beach has involved the public health, voluntary and private sectors in implementing an AIDS "network" to assure a cost-effective full-range of health, economic and social services to HIV victims. The Health Department works very closely with the Comprehensive AIDS Program (CAP), administered by Mr. Louis Max, private practicing physicians and several hospitals, particularly St. Mary's Hospital in West Palm Beach and Everglades Memorial Hospital in Pahokee in western Palm Beach County. The Palm Beach Board of County Commissioners also has undertaken a major expan-

sion of its County Home and General Care Facility (an extremely well staffed and equipped nursing home) to include a 30 bed unit dedicated to AIDS.

Medical care is available to AIDS patients at several health department sites, most notably in West Palm Beach, the Delray Beach Health Center in south county and the C. L. Brumback Health Center in western Palm Beach county. In West Palm Beach clinics are held three times weekly: Monday morning clinics for patients on AZT or with physical medicine or neurological symptoms, Tuesday afternoons for cases of AIDS and ARC (AIDS Related Complex) and Thursday afternoons for AIDS patients with tuberculosis. The staff of these clinics include a health department internist, five infectious disease specialists, a neurologist/psychologist, nurses and counselors and, an attorney from the Legal Aid Society to assist patients, as well as CAP multi-disciplinary staff.

In western Palm Beach County the C. L. Brumback Center has a number of well-trained National Health Service Corp internists and pediatricians. Since a number of medical sub-specialists are not located in this agricultural area, services are coordinated closely with the coast.

At the end of June, 1987, 150 patients with AIDS and ARC were being treated in health department clinics.

INPATIENT SERVICE:

Palm Beach County has no countywide governmental hospital such as Jackson Memorial Hospital in Dade County. All hospitals in our county have cared for AIDS patients. St. Mary's Hospital in West Palm Beach treats the majority of AIDS patients. Private sector internists contracted with the health department to deliver hospital care at St. Mary's Hospital; the National Health Service Corp physicians deliver care at Everglades Memorial Hospital.

HOME HEALTH:

The cost of caring for AIDS patients is high, especially in programs emphasizing hospital care. Providing medical services at home and non-hospital alternatives cuts costs and allows patients to remain in their own environment. The Comprehensive AIDS Program of Palm Beach County (CAP) is a program emphasizing home health services that was established by an innovative grant from the Robert Wood Johnson Foundation. It includes personnel in coastal and western Palm Beach County. This staff provides all levels of care from home health aides to high tech at-home intravenous antibiotic therapy. Social workers assess need in areas such as housing, disability, legal issues, and psychosocial concerns. Volunteers are utilized for many services. CAP and health department personnel work closely together. Weekly interdisciplinary care conferences are held. At these meetings, patients' needs are reviewed, assessments determined, and plans made for treatment.

EXTENDED CARE:

The Palm Beach County Home and General Care Facility provides extended care for AIDS patients in Palm Beach County. Health Department and CAP personnel work closely with County Human Services and County Home social workers to provide appropriate placement. This facility presently has seven beds. Expansion to 30 beds for AIDS is underway and should be complete in early 1988.

HOSPICE:

Hospice of the Palm Beaches provides terminal care to eligible patients and families.

PREVENTIVE HEALTH EDUCATION:

In the absence of an effective medical cure or a preventive vaccine against AIDS, preventive education is the only effective weapon we have for slowing down the transmission of this deadly virus and preventing disease.

The Palm Beach County Health Department has taken the lead in developing a network of AIDS preventive education programs and activities by providing these services directly through its public health nurses and health educators, and by training other community groups and organizations to provide these services.

SUMMARY:

In summary, Palm Beach County has undertaken a comprehensive cost-effective approach to the treatment of AIDS victims and the prevention of AIDS transmission. We have worked closely with numerous community groups and organizations to develop one Palm Beach County "Comprehensive AIDS Program".

I am encouraged that a nationwide Commission on Acquired Immune Deficiency Syndrome Task Force has been appointed by President Reagan. We are at war with a most deadly enemy, the AIDS virus. We cannot afford anything less than a very well organized, balanced national strategy.

The day-to-day, person-to-person prevention and treatment actions are at the local community level. Proper fiscal and programmatic support and leadership from national programs must reflect this fact.

Lastly, most difficult public policy issues concerning civil liberties and police powers will challenge us to maintain a most difficult balance between individual privacy and freedom, and protection from this lethal virus.

FUNDING

Funding for the various aspects of AIDS care is summarized below:

	86 - 87	87 - 88	88 - 89	89-90
Robert Wood Johnson	443,592	394,323	385,038	377,047
State of Florida	200,000	350,000-400,000 (Projection)	?	?
CDC HE/RR (BG)		314,000	314,000	314,000
Educators (FL)		51,000	51,000	51,000
United Way (JD)		20,000	20,000	20,000

HOW IS MONEY SAVED BY THE PALM BEACH COUNTY PROGRAM?

OUTPATIENT CARE	Continuity of medical care providers prevents costly repetition of workups Early diagnosis of complications may prevent hospitalization Contracts with providers in the community assure best price for services rendered
INPATIENT CARE	Continuity of medical care from outpatient setting continues to prevent costly repetitious workup. Discharge planning in coordination with the hospital eases early discharge with follow up visits in the home by program nurses. Hospitals are paid a per diem rate set by contract.
INTERDISCIPLINARY STAFFING	Care plans are formulated which emphasize preservation of functioning and encourage home health services.
HOME HEALTH CARE	Costly services such as IV infusions may be provided at home. Use of home attendants reduces the need for extended care facilities. Timely visits by home health personnel prevents unnecessary use of Emergency Rooms. Knowledge of home situations helps develop care plans based at home.
PSYCHOSOCIAL SERVICES	Maximizing social services available assures early entry into medical care preventing costly complications.

	Patient education regarding the course of illness often results in decisions to forgo intensive care in terminal stages. Use of peer support groups reduces the need for outside psychological resources.
EXTENDED CARE	Nursing home beds are used to dramatically reduce the length of hospitalization. Continuity of medical care reduces repetitious medical workups.
HOSPICE	Terminal stages are treated at home instead of in hospital or nursing home. Family education prevents panic and irrational use of medical services.

WHO SAVES MONEY BY THE PALM BEACH COUNTY PROGRAM?

PALM BEACH COUNTY	Indigent inpatient care is funded by County Human services. Expenses are reduced by (a) decreasing stay of hospitalizations (b) eliminating repetitious medical workups through continuity of medical care.
STATE OF FLORIDA	The Medicaid program would save outpatient dollars because (a) continuity of care prevents repetition (b) complications are recognized at an earlier course in the disease The Medicaid program would save inpatient dollars because (a) length of hospital stay is reduced (b) continuity of care

FEDERAL GOVERNMENT	Preserved functioning may reduce amount of benefits necessary for disability
THIRD PARTY INSURERS	Continuity of care is provided. Length of hospital stay reduced.
SOCIETY	Preserved functioning reduces burden on society

COST COMPARISON OF A TYPICAL PERSON WITH AIDS -- ACUTE CARE

A 25 year old homosexual white male with a known positive HIV antibody complains of shortness of breath. Expenses for care in the two settings are categorized below:

INPATIENT CARE		OUTPATIENT BASED CARE	
16 day hospital stay	$12,000	bronchoscopy	$500
physician's fees	$2,500	IV antibiotics (14 days)	$1700
		blood tests	$182
		x-rays	$52
		oxygen	$700
		physician's fees	$320
TOTAL FOR INPATIENT CARE	$14,500	TOTAL FOR OUTPATIENT CARE	$3454

USE OF OUTPATIENT CARE CAN SAVE OVER $10,000 IN ACUTE CARE SITUATIONS !!!

Dr. FISCHL. I'd like to thank you for this opportunity to testify today. And we'd like to really share with you our experiences in caring for adult patients with AIDS at our medical center. And I'll try to focus mainly on patient care issues that we have addressed and touch just a little bit on clinical research.

Our medical center serves not only as a primary health care for more than one-half of the patients with AIDS reported in the State of Florida, but it also serves as a tertiary referral center for difficult cases of medical management and diagnosis.

This is also a major research center for the development of new drugs and therapies.

The care and treatment responsibilities that have impacted on our center, and many similar centers throughout the country is not infrequently overwhelming. To date, we have cared for close to 2,000 patients in our facility with AIDS or AIDS-related illnesses. We have screened over 5,000 patients for HIV infection and have evaluated over 1,000 patients for research protocol. By the end of 1985, we were seeing approximately 40 to 45 new cases with AIDS or AIDS-related illnesses per month, we had scheduled over 2,000 clinical appointments in our out-patient clinic or research program. On the average our in-patient bed census had climbed to 40 to 45 adult patients with AIDS at any one time. The average length of hospital stay was between 14 to 36 days, and the average cost for health care for a single patient over a 2-year period was close to $125,000.

Senator CHILES. $125,000 average cost over a 2-year period?

Dr. FISCHL. Yes; per patient.

Senator CHILES. Per patient.

Even though a lot of those average people were only there how many days?

Dr. FISCHL. Anywhere from 14 to 36 days.

Mr. CHILES. Fourteen to thirty-six days.

Dr. FISCHL. Based on these figures and the increase in the projection of the incidence of AIDS, we estimated that by 1989 more than 50 percent of our resources in the department of medicine would have to be directed to care and treatment of patients with AIDS and AIDS-related illness. Because of this, we began to implement very quickly alternative ways or novel ways of caring for patients with AIDS and AIDS-related illnesses. And through the assistance of the Health Resources and Services Administration, the Robert Wood Johnson Foundation, State of Florida, we have been able to build an ambulatory day treatment center, extend critical community resources, are in the process of building a 36-bed in-patient unit, and have a temporary unit presently in our in-patient services.

These facilities and programs have allowed us to decrease the need for hospitalization, decrease the length of hospitalization, and to treat the patients in an out-patient setting or home infusion program and to seek assistance from community hospitals and physicians in sharing the burden of health care cost.

In implementing those programs we've also focused on new and novel ways of making the diagnosis of infections that can be done in out-patient settings and institution of treatment and a continuation of treatment in an out-patient setting. Because of this program despite an increasing incidence of AIDS, we now see approximately 16 new cases of AIDS per month in our facility and probably will have over 7,000 appointments scheduled in our patient clinic and research areas. Our average in-patient census has fallen to 15 and 20 patients at any one time. The average length of hospital stay has decreased to 7 to 14 days and the estimated costs now per patient in this program, over a 2-year period, is estimated to have decreased by a factor of 50 and perhaps 75 percent.

Senator CHILES. So we're down to less than one-half of that $125,000 average cost that you had before?

Dr. FISCHL. Yes.

Senator CHILES. Now aside from the money—the money is always important, but aside from the money, what about the quality of care for the patient or the humaneness or anything else, is it as good as it was if you have strict hospitalization or not?

Dr. FISCHL. I actually think it's better.

Senator CHILES. Better?

Dr. FISCHL. By looking for novel ways of making diagnoses, for example, to make a diagnosis of *pneumocystis carinii* pneumonia, which is the most common infection in patients with AIDS, it required hospitalization and a lung biopsy and a protracted hospital course. Now, by simply inducing sputum with a salt solution, if this is done carefully, it can be done in an out-patient setting and 65 to 85 percent of the time we make a diagnosis of this pneumonia. It also allows us to make a diagnosis early and to intervene with treatment early. So, therefore, if we can look at the identification of infections and treatment of infections much earlier or make those diagnoses, treat them in an out-patient setting and this has clearly improved the quality of life and also has increased longevity in patients with AIDS. So I would say that——

Senator CHILES. This is one of those happy incidences where the cost is better but also the quality of care is better as well.

Dr. FISCHL. And it also allows the use of community resources and, therefore, a much more comprehensive program in the care of patients.

I think it also takes them out of a hospital setting which can be very debilitating to them and not meet all their needs.

I think part of the success of this program has also been education of primary case physicians in the community and an increasing recognition and responsibility of physicians in the community and hospitals to actually care for patients with AIDS. And to extend this we have established a network of community physicians interested in developing treatment programs for AIDS patients. We are trying to include educational programs to work with these working physicians to give them the latest information about AIDS, to bring to them the techniques that we're using in our clinic, and to try to teach them these techniques. So

one area where funding desperately is needed now is to implement these new programs that are being developed at these medical centers to physicians who work into the community and to continue this education program.

The other area where we really see a need is that a majority of our patients are from the inner city, economically depressed areas, and health care clinics and medical centers that are in these areas, servicing these patients, are going to have to step up their educational programs to educate their health care professionals and physicians in these areas to actually take on the responsibility of recognition of infection with this virus, recognition of AIDS and AIDS-related illness.

Finally, I'd like to focus just a little bit on our research program. We are one of the major centers looking at testing, treating AIDS virus, treating the infections that we see in patients, treating the cancers that we see in AIDS patients. We expanded our research unit three times and I now have over 35 individuals that work strictly on research protocols. We are testing 15 different drugs and various protocols at this time through the assistance of the Centers for Disease Control, the NIH intramural programs and industry, we have been able to rapidly build this program. However, funds which pay for the direct costs associated with these research projects are important but are not sufficient for development of a comprehensive AIDS research program.

The growth in AIDS and AIDS-related research within the academic center has completely put a strain on our ability to find space, to find capital, equipment, or administrative support.

In addition, there are tremendous hidden costs in implementing national programs and taking our workers out of the research setting to participate in national policy. It is very clear that we need to develop a comprehensive AIDS research program throughout the country, and core support for those programs is desperately needed.

Finally, we realize that an education process is needed and it's desperately needed to educate individuals, to train them to work in the area of AIDS and to work in the area of research. It has become very obvious to me that over the next several months, if not year, we're going to face a critical shortage in physician manpower, nursing manpower, and other medical personnel, to actually work in these treatment areas for AIDS and to actually work in research areas. Most of the individuals that have a self-interest to work in this area have already been recruited. It is very time consuming, it is a full-time job 24 hours a day, and I think we need to begin training programs immediately because as we expand these programs I think we're going to face critical personnel shortages very quickly.

In summary, I think it is clear that new and alternative and novel programs for patient care and research are underway but continued expansion into the community, education and training programs are desperately needed.

I'd like to thank you again for this opportunity and I'll try to answer any further questions that you may have.

Senator CHILES. Thank you. I'll take the testimony of all the panel and then we'll have some questions. We'll hear from Dr. Howell.

STATEMENT OF JAMES T. HOWELL

Dr. HOWELL. Thank you. Palm Beach County has got a different setup, we do not have a tertiary referral center so the format of the program is very different. But I think the same matrix of comprehensive care and community, primary care base, clinic base is the same.

We've recently, in early July, passed 300 patients, full-blown CDC AIDS patients in the county. We have hundreds more that are—literally thousands more that are infected with the virus. We're presently treating 158 patients or AIDS-related ARC patients in our clinic.

We have—the Palm Beach County Health Department basically runs the primary care clinic for the medically indigent in Palm Beach County using the private sector for a great deal of the specialty care and using area hospitals. We also do not have a countywide hospital as compared for example to Dade County. I don't think you can—We can't underestimate the economic force Representative Frankel had mentioned and the social and health costs.

It is a constant treadmill and I've described the public health department as sort of being before and after AIDS. Before AIDS life was a lot easier as a county health director than after AIDS.

The key word that I would like to stress is networking. We do not have CPA-audited accounts but I think that we would show a cost of treating AIDS patients as out-patients with a proper medical comprehensive AIDS program, which Lou Max will be speaking about in the next panel, would really diminish costs and Dr. Fischl has said increase the quality of life. No one wants to spend unnecessary days in a tertiary or hospital facility.

We use St. Mary's Hospital primarily here on the coast where we have private practicing internists who do our hospitalizations. In our clinics here on the coast we have infectious disease internists who are on contract, we have neurologists, we have urologists, and most medical specialists on referral. We have an interesting United Way grant through the local Legal Aid Society that gives us a very fine young attorney who needs to work through a myriad of everything from SSI eligibility to other issues.

In western Palm Beach County, which is Belle Glade, Pahokee, and South Bay and so forth, we, we also as you know, have a major AIDS problem, about one-third of our cases come from that area of the county. And there we do most of our hospitalization at Everglades Memorial in Pahokee and we have a very fine set of National Health Service Corps physicians, pediatricians, and internists who do most of the onsite specialty care.

Again, to go quickly, we try to focus on the patients. We have the home health care, we have the extended care which Commissioner Adams here this morning has been a very forceful person in getting our county home which is really more like a chronic disease hospital, a very

fine facility which will be expanded to 30 beds dedicated to AIDS patients in early next year as an intermediary care facility and hospice.

I would just like to highlight that education right now has to be our major, our major tool for prevention and that's very hard. I know, Senator Chiles, you've been very instrumental in public policy in regards to drug abuse. And cocaine and AIDS in Palm Beach County are interwoven. Obviously a promiscuous lifestyle, and we talked about how we were going to get the women off the street when—and counsel them on AIDS when you can't get them off their cocaine addiction. And that becomes on Mazlow's scale a No. 1 issue. So both of them are really interrelated.

I would like to see much more massive education plus targeted education to the high-risk groups, and in our county we have a very high percentage of minority populations. And I think, I think we have got to do more than—I know we're going to do a study shortly—not a study, a program shortly in western Palm Beach County with CDC and HRS in regard to trying to target the high-risk behavior activities out there. But that's going to take a lot of—that's almost one-on-one type of education so you have different levels of education.

The last comment that I would make is that the people on the front line, that we need strong Federal leadership. And it's a very complex issue and it may change day to day, and I think that given the state of the arts we appreciate that local level but to—really to try to build it around the local delivery systems that are emerging throughout, around the country, because this is when the—when the AIDS patients or the family are distraught or we've got people in the anonymous testing center, it's really at the local level where we're really going to hopefully make the impact.

Thank you, sir.

Senator CHILES. Thank you, Doctor.

Dr. Droller?

STATEMENT OF DAVID G. DROLLER

Dr. DROLLER. Senator Chiles, thank you for providing me the opportunity of testifying at this committee hearing.

I am a physician in Broward County presently in the private practice of a subspecialty called infectious diseases, a subspecialty of internal medicine. I have been caring for AIDS patients with acquired immune deficiency syndrome since the recognition of this new illness in Broward County in 1979.

Since 1980 the number of patients satisfying the Center for Disease Control case definition of AIDS has risen dramatically in Broward County. For example, over the last 2 years, the number of newly diagnosed cases of AIDS at a particular tax-subsidized medical center in Broward County has risen from 75 per year in 1985 and 1986 to 50 in the first 4 months of 1987, the number continuing to arise unabatingly. The number of people hospitalized at this particular institution with AIDS at and one time has been 15 to 20 at a conservative cost of $500

to $1,000 per day per person. These numbers do not include those infected with the human immunodeficiency virus, yet not satisfying the case definition of AIDS. Presently 40 percent to 60 percent of my office practice is involved in the care of those people with AIDS and the complications of HIV infection.

Most of these victims are either indigent, underinsured or shortly will be uninsured with regard to medical expenses. Many are discharged from their jobs, or are too ill to return to work, and, therefore, unable to assume payment of health insurance premiums. As a consequence, to the enormous psychologic trauma of knowing they have a lethal disease is added the additional onus of trying to obtain and pay for medical care and basic subsistence.

Based on a projected number of patients with AIDS in Broward County of approximately 4,000 by 1990, and assuming at least 50 percent of these will be unable to afford medical care, we can anticipate conservatively 1,500 to 2,000 patients with AIDS needing care in an out-patient ambulatory setting. These projected numbers do not include those who are asymptomatic or have other complications of HIV infection which do not meet the CDC definition. The total may be 50 times the number projected with AIDS. These numbers also do not reflect the increased life expectancy as newer modalities of treatment . are discovered and developed.

In anticipation of the rising number of people with AIDS and HIV-associated disease, the Broward County Public Health Unit, under the direction of Dr. Charles Konigsberg, has initiated the development of an out-patient ambulatory facility to help deal with the many medical and social problems encountered by those with HIV infection.

This clinic is being staffed by private practitioners from Broward County who have had experience in dealing with the many medical complications of AIDS, and who have volunteered their time from their private practices. It is anticipated that this out-patient facility can serve as the hub of a network along with the various tax-subsidized hospitals, to serve the complex medical and social needs of those with HIV infection.

As can be appreciated, the costs involved will be enormous. It is hoped that with the help of county, State, and Federal funding, care for the victims of this devastating illness in Broward County can be provided in a humane, yet cost-effective manner.

Thank you for your kind attention.

Senator CHILES. Thank you.

Let me ask you, we understand there is a doctor surplus yet it's very difficult to find doctors that will work with AIDS patients.

Dr. Droller, you're a practicing private physician, not in the public health business, you're a little bit different from Dr. Fischl and Dr. Howell in that regard. Why is it difficult in Broward County—and Dr. Fischl, how do you see and what are we going to do to be able to get physicians to work with AIDS patients?

I heard you mention, Dr. Fischl, the need for education. It looks like as much as we need to educate some of the prospective or potential AIDS victims, we also need a lot of education for physicians as well.

Dr. FISCHL. I think there is no doubt about that because especially as we're going to see patients who go to clinics in inner city areas, go to Public Health Service-type clinics, physicians in those facilities will need to be educated as well as general practitioners. I think we are also going to have to deal with the potential risk to health care workers and are going to have to define very concretely what are the policies for health care workers in caring for patients with AIDS and AIDS-related ilinesses——

Senator CHILES. Obviously as we go through this out-patient mode we will have to do that. Thank you very much.

Dr. Droller?

Dr. DROLLER. I think there are a number of factors, one, of course, is fear. And what Dr. Fischl had mentioned, in terms of educating physicians, there is a fear of becoming infected with the virus among the health care providers. I've seen that with colleagues of mine who've refused to take care of certain patients, perform certain procedures ostensibly because they're not, someone may not survive, but, in effect, what they're saying to me is that they're scared, they don't want to get the disease.

The other thing which is a major problem is that we're dealing with a large number of indigent patients. The State Medicaid system just does not pay for the car of these patients. I know in my personal practice I generally—although I have some people with Medicaid who come to the office—I generally don't because they just—what Medicaid pays, if it pays it all, does not, will not cover even my expenses.

I think many, many of my colleagues have also found that, that dealing with the bureaucracy of Medicaid has not been worth it and they cannot, they cannot afford it. They cannot afford to assume the expenses or the liability of caring for someone with such a devastating disease, not being able to provide it.

Liability is another problem which actually we have faced in terms of the Broward County Public Health Unit facility, this in trying to recruit many of the physicians who are taking care of—who will be taking care of those patients when a major topic had come up, which was the liability of caring for someone who has this devastating disease. How are these physicians going to be covered? It hasn't been answered satisfactorily yet, but presumably we will be under protection, some type of protection from the State. But that was a major—this has also a major concern among the private practitioners in caring for people with AIDS in this clinic. And hopefully this will have been worked out.

So there are a number of factors in terms of trying to obtain physicians to take care of these patients.

Senator CHILES. Well, I assume that both of you are saying with the proper knowledge, education, and care, a physician or health aide can treat AIDS patients and be able to protect in that regard if they——

Dr. FISCHL. Yes.

Dr. DROLLER. Yes.

Senator CHILES. So the answer is more one of education and training and you're mentioning these other factors but there has to be some kind of compensation in the liability question.

Dr. DROLLER. Yes; those were the other factors.

Senator CHILES. Dr. Fischl, could such a system as you have developed, you all are developing in Dade County, especially having to do with the out-patient treatment and out-patient detection that you're doing, could that be transferred to other counties?

Dr. FISCHL. Yes; I think so.

And I think that is one of the other important issues related to ambulatory care because we look at novel ways of treating patients that don't require special technology, that are not necessarily very expensive but are effective and can intervene early and that would be just the appropriate program to transfer to other facilities to get them started.

Senator CHILES. With some of the moneys that you're receiving from the NIH and other grants that you have, the Robert Wood Johnson grant, are you trying to develop such a model or——

Dr. FISCHL. Yes.

Senator CHILES [continuing]. Is someone——

Dr. FISCHL. Yes.

Senator CHILES [continuing]. Or the county seeking your help, your expertise whether the State of Florida or somewhere else that could get some information, a kit or——

Dr. FISCHL. No; not yet.

Senator CHILES. Not yet.

Dr. FISCHL. One of the areas that we do have problems with is since we're all literally in the trenches doing the work——

Senator CHILES. Right, right.

Dr. FISCHL [continuing]. It is now trying to translate that into a program that we can present to other physicians, other programs and that development is underway right now. We do have to do it with our own internal resources, so it's slow going.

Senator CHILES. Right. But that is something that you're working on now, you need further assistance in that and it seems to me that is something that is awfully important.

Dr. FISCHL. I think it's critical.

Senator CHILES. That we try to get some kind of an off-the-shelf model that you can send or be able to give to——

Dr. FISCHL. I think assistance now in taking these programs and getting them, presenting them across the country is essential.

Senator CHILES. Well, as we look at the number of cases and the progression and the way, the geometric progression and that's what we're seeing here, both for the, again, the proper treatment and for the cost of it, it looks like we've got to try to do this.

What do each of you believe are areas which are still inadequately addressed by the Federal budget? You've heard some of the priorities

that we're talking about. I think you know some of the areas that we're talking about.

Dr. HOWELL. I'm still concerned and we need a strong national policy direction. And I think we need the health education, it still appears to me to be fragmented. I don't know if that's a budget—I'm not smart enough to realize whether that's a budget issue or a policy——

Senator CHILES. Well, I think it's more policy right now. It may be a budget issue later, but we're groping, really trying to find out where to go. And I think again we're battling these things, general education we have out there, as you start getting, targeting to people, you know, how do you best do that, how specific can you be in television and those other areas. What is the most effective way, you know, we're searching for that.

Dr. HOWELL. I guess another area would just be a networking. Even throughout Broward, Dade, and Palm Beach County, they differ in their, really their makeup of their medical model and their social service delivery systems. I think that the out-patient care, the social service, the community support and it—you all may want to look at having some incentive dollars to communities that haven't done that yet to really sort of almost like you hold a health planning day with implementation factors to really get out and pull those matrixes together.

Dr. FISCHL. I mean to extend that. I think that is going to be an important area to continue funding and to actually extend these models out into the community and to set in place educational programs that will educate those physicians and also funds to allow team or network for development of these programs throughout the country.

Dr. DROLLER. I'm not a researcher but since no one has mentioned the research and where the funding should go, I think clearly the key in the whole thing is prevention, prevention of transmission, early intervention and some basic science and I think even though I as well as others are the trenches, taking care of people with this problem, clearly we're trying to close the barn door after the cows are out. So what I would make a plea for, even though we're hurting as clinicians, I'm making a plea for money being put into the epidemiologic treatment and basic science research, because I think that's where this war is going to be won and not in the—although important, but not necessarily only in caring for these people.

Senator CHILES. I think that's an area in which we are putting large amounts of money and we're increasing that amount this time again.

Like any research, you have to be somewhat careful, because as Dr. Fischl has pointed out, there are only so many people that are there and you want to make sure that you get effective, you know, results from the money and build up of that can only go at a certain pace or you simply squander your resources and don't get the products from your work. But I think if you look back over that curve, you can see that it's a pretty steep funding curve.

I want to thank each of you for your testimony, it's been very helpful to me and I hope you will feel free to communicate with us. We're

trying to put together this plan and we want to continue to hear from you and we thank you for the work that you all are doing in the trenches.

Dr. HOWELL. Thank you, Senator.

STATEMENTS OF:

WADE PARKS, M.D., MEDICAL VIROLOGIST, DIVISION OF IMMUNOLOGY AND INFECTIOUS DISEASES, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF MIAMI SCHOOL OF MEDICINE

GWENDOLYN B. SCOTT, M.D., ASSOCIATE PROFESSOR OF PEDIATRICS, DIVISION OF INFECTIOUS DISEASE AND IMMUNOLOGY, UNIVERSITY OF MIAMI SCHOOL OF MEDICINE

CARL EISDORFER, PH.D., M.D., PROFESSOR AND CHAIRMAN, UNIVERSITY OF MIAMI DEPARTMENT OF PSYCHIATRY; DIRECTOR, BIOPSYCHOSOCIAL CENTER FOR THE STUDY OF AIDS

Senator CHILES. Our next panel of three physicians works in AIDS research and treatment of pediatric AIDS cases. All three of our panel, Dr. Wade Parks, Dr. Gwendolyn Scott, and Dr. Carl Eisdorfer, from the University of Miami, work with the State of Florida, Jackson Memorial Hospital, we'll bring you up here and——

I want to take a brief recess, we'll be right back.

[A brief recess was taken.]

Senator CHILES. Dr. Scott, we'll start with you. Again, brief your statement for so we will have time for questions.

Dr. SCOTT. Thank you.

I'm Gwendolyn Scott. I am a board certified pediatrician with specialty training infectious disease at the University of Miami School of Medicine. I direct the clinical research efforts in children with AIDS at Jackson Memorial Hospital. Our group involved with many areas of research in children funded by the National Institute of Health, the National Institute of Mental Health, and the Florida State Developmental Disabilities Council. We also participate in the AIDS treatment and evaluation unit and are presently involved in phase one drug studies in children.

My expertise in AIDS is derived from personal experience with the care and treatment of 170 children with HIV infection that we've seen at our medical center since 1981 as diagnosed by the CDC. Of those children, approximately 55 have AIDS. The remainder are clinically symptomatic but do not meet the CDC criteria for diagnosis of AIDS. We do serve as a major referral center for children diagnosed with HIV infection in south Florida. Our average in-patient census in Jackson Memorial Hospital at this time is 12 children with HIV infection and we follow approximately 90 children in our out-patient clinic.

The majority of my experience in AIDS has been in infants and mothers and most of my comments this morning will be restricted to these groups. I think that the importance of pediatric AIDS has not yet been fully appreciated and funding of research in this area has lagged behind that of adults. Women also are more recently recognized and it's impressive that the greatest percentage increase in identified cases over the past year has occurred in women.

As of July 27, the CDC had received 551 case reports of AIDS in children. Again, as I indicated from our experience, this is really only the tip of the iceberg since there is a broad spectrum of disease and only those with the more severe disease are recognized by the CDC. Thus, this number underestimates the number of infected children. There are also 153 adolescent cases that are reported to the CDC with AIDS and I think that this is a group that is generally forgotten about. It is estimated that the doubling time for pediatric cases presently reported is 13 months. At Jackson Memorial Hospital in this year we are identifying one new case of pediatric HIV infection per week. In children under 13 years of age, the majority of infection occurs as a result of perinatal transmission. In other words, from an infected mother to her infant. An infected mother can transmit the virus to her infant across the placenta during pregnancy, at the time of delivery, because of exposure to infected secretions or possibly postnatally by ingestion of infected breast milk. In the 13- to 18-year age group, the causes of infection are more similar to those in adults.

What's the profile of a typical child with AIDS? This child is an infant or toddler, usually under age 2, who lives in the inner city in a large metropolitan area. His parents are poor, nationally 54 percent are black, 25 percent are Hispanic, and 21 percent are caucasian. In Miami, 95 percent of our cases occur in black children, 3 percent in Hispanic, and 2 percent in caucasian. In about 70 percent of the cases nationally, mother or father have a history of drug abuse. In our population in Miami, 23 percent of the parents with HIV have a history of drug abuse.

A few children have developed disease from blood transfusion or blood product transfusion, but the majority of children have disease from parents who have disease from heterosexual transmission.

Senator CHILES. Not IV?

Dr. SCOTT. No; this is presumed heterosexual transmission, no history of IV drug use.

What is this child's progress? It's very poor. National statistics suggest that once a child is diagnosed with AIDS that the median survival is less than 1 year. And I think that this points out the importance of early diagnosis and early treatment programs as they become available in these children.

In terms of children there are many basic questions that are still unanswered. We do not know whether the majority of transmission occurs before, during, or after birth. We don't even know what proportions of infants born to infected women themselves will be infected. We don't understand what factors enhance transmission perinatally from mother to infant. In addition, the diagnosis in the newborn is complicated because mother transfers antibody across the placenta at the time of delivery. Therefore, newborns of HIV positive women will always be HIV positive at birth, however that does not indicate that they are necessarily infected because this antibody can persist for long periods of time in infants, even up to 12 or 15 months of age. Many times we cannot

icate a definite diagnosis in a child for many months, even up to 15 nths of age.

'ediatric AIDS is also important because the child is frequently the t case identified in the family. Most of the women that we have seen asymptomatic at the time of delivery of their first child with AIDS l they're unaware that they themselves are infected so that the pedia- case serves as an index case in the family. In fact, we consider inatal disease a family unit disease because as we look at the parents, ier siblings in the family, the mother is obviously infected, the father y or may not be infected, and many times other siblings are also in- ted.

This, of course, because it's a family unit disease, poses very special oblems in pediatrics. Many times the parents become ill, too ill to e care of their children, sometimes they die and the children are left hout a home, giving us problems in terms of placement and foster e for those children.

How can we impact on this disease? Well, I think efforts need to be ected toward reduction of transmission and early diagnosis and treat- nt of infants. For this to be successful, women must know their HIV tus. Women need to be offered testing and counseling.

f the disease is acquired while the fetus is in the uterus, then per- os treatment of the mother with antiviral drugs would be a logical o. If the disease occurs at the time of delivery or thereafter, an ap- oach could be utilized similar to that of hepatitis B where you give h titered immunoglobulin as well as vaccine. In the case of HIV, one ld produce a high titered HIV antibody and give either antiviral gs or vaccine as it becomes available to these infants in the hope of venting disease.

This disease takes its toll early in children. Thus it is urgent to de- r available treatment early and it's important that these children be ntified. There is no less urgency to do this in children than in adults. Finally, the adolescent or college student are forgotten groups. Little known about the incidence in adolescents and I think the develop- nt of model programs for education and counseling of these groups mportant. I would also stress the special problems children present, ticularly with foster care, day care, and school attendance.

n closing, I would recommend continued funding of natural history dies and studies of transmission in mothers and children. Additional ds should be allocated for the study of organ specific diseases such he central nervous system, the heart, lung, and kidney.

pecial consideration should be given to the development of new and rovement of present diagnostic tests, particularly in newborn infants. derstanding of the molecular biology of this virus and its genetic keup is essential to understand the pathophysiology of the disease to be able to develop new antiviral drugs and a vaccine.

upport for the development of antiviral drugs is crucial. It's also im- tant that these drugs be made available early for children. Tradition- children in general are only put into vaccine trials after the drugs

have been well studied in adults. I think that the urgency in children is as urgent as in adults and we need to start these drug studies early. Treatment programs should be targeted to prevention or modification of disease in newborn infants by treatment of the HIV positive pregnant females or the newborn infants. Our goal is to treat all children. If we are going to do that, then funds must be allocated for the treatment of these children and adults who are infected. Other potential therapy such as the development of high titered antibodies should be supported and vaccine developmen should be a priority.

I thank you for this opportunity——

Senator CHILES. Thank you.

Dr. SCOTT [continuing]. In light of our experience.

Senator CHILES. Thank you, Doctor.

Dr. Eisdorfer?

STATEMENT OF CARL EISDORFER

Dr. EISDORFER. Thank you, Mr. Chairman.

I am Carl Eisdorfer, professor and chairman of the department of psychology at the University of Miami and chief of mental health services at Jackson Memorial Medical center and as of recently the director of the university's Biopsychosocial Center for the Study of AIDS. This is a project funded by NIMH, the National Institute of Mental Health jointly with the National Institute of Drug Abuse.

My focus today will be on the neuropsychiatric aspects of this tragic disease. Our efforts at mastering the virology and immunology of the HIV infection, and efforts at immunization and treatment are critical. However, as we come to understand the spectrum of disorders associated with AIDS, We must also recognize that behavioral and neuropsychiatric issues play a major role in patient care as well as in managing disease spread.

The vast majority of patients with AIDS die with central nervous system lesions, estimated over 90 percent. AIDS is transmitted primarily by specific types of behavior, both sexual as well as IV drug use.

AIDS then, from its inception, fits the model not just of a simple infectious disorder with a virus but of a biopsychosocial disorder involving an infectious agent, but also the individual's reactions to the agent, the consequences of that reaction and the factors involved mediating that reaction during the course of infection and disease. Simply put, stress and emotion both in the community and in the individual play a role in the dynamics of the disease and the way it's spread.

Persons at high risk for AIDS include not only a wide spectrum of individuals which well known now, but as you just heard, newborns of infected mothers and individuals of both sexes who are sexually active with multiple partners. As a result, many adults at risk, even whole communities, join in what has been described elsewhere as the worried well. I've had several interviews with gay men and others who have stated that the illness, death of their friends, lack of a vaccine, the risk of unemployment or loss of employment for disclosure, potential cost of

care, family upset and arrest—reactions familiar to all of us who take care of patients with AIDS—have led them to desperation.

Many of those who are concerned come in for testing and undergo a period of serious anxiety until the test data are available to them. During this period support, counseling and psychosocial intervention are crucial. Testing without such support, I feel, is deplorable and is a concern, I think, that should be addressed nationally.

In all laboratories we're studying the value of counseling and stress reduction as well as such factors as physical exercise and other mediators to help deal with the consequences of testing.

Uncertainty and fear about eventual outcome of their condition is a problem among those who test positive. Pressure to alter their intimate personal and sexual behavior, which in the past probably had a supportive effect for them, leads to a host of repercussions including loss of friends and loss of employment, which are only a few of the problems encountered. Here we'll see a high bodily concern about any physical change and often an association of depression with sadness, guilt, lowered self-esteem, suicidal thoughts, and suicide. This is again associated with a sense of isolation confounded by the actual reduced support of individuals normally close to the infected person.

Since there is already evidence that the depression and stress have a negative effect on the immune function independent of AIDS and since impaired cognitive functions makes management more difficult, these are not trivial issues.

AIDS dementia has now become an issue of major concern in the country. The early view was that the HIV-infected individual developed AIDS or AIDS-related complex, and the face of immune system collapse would develop a secondary infection.

About 1½ years ago reports were published which pointed out that the virus would and could directly infect the brain even before the changes in the blood which characterize AIDS as a disease—this so-called T–4, T–8 cell ratio, which is well known. Primary AIDS dementia is now a well recognized phenomena with tragic consequences. Its features involve an insidious onset, with significant forgetfulness, mental slowing, poor concentration, and a range of motor symptoms. As you heard, in individuals with AIDS, all show developmental tags relatable to the central nervous system.

Perhaps oversimplistically I can describe AIDS patients as showing a set of neuropsychiatric disturbances characterized by four D's, denial, depression, delirium, and dementia.

Patients with denial, they simply deny they have the disease although they know at some level that they have been exposed, constitute a particular problem in that their behavior as individuals makes management difficult. Their behavior as social individuals makes them a problem in an effort to contain the disease spread.

The delirious patient, so-called, shows signs of profound mental illness, very often mental schizophrenia.

The depressed patient is often a suicidal risk but equally important depression clearly also adversely affects the immune system in its own right.

These conditions about which we are just beginning to learn need not only concurrent help but intensive investigation.

Enough cannot be said about the need for caring for the caregivers, those who provide daily support for these complex patients. Dealing with the profound infections relatable to AIDS or cancers is difficult enough. Add to this the perceived risk of possible personal infection and the behavior of some patients whose psychiatric problems make them hard to cope with and the issue becomes more acute. Volunteers, particularly the gay community, have worked in this country with great effort in a number of settings. It is estimated that well over 100,000 hours of volunteer time were donated in the San Francisco community last year alone. Volunteers, however, may feel considerably less enthusiasm as the population of AIDS patients becomes more heterogenous and other groups are simply not stepping forward in cities around the country to help with this growing problem.

Simply put then, relying on volunteers is a bad way to plan for the future is vastly expanded clinical needs. The patient with impaired emotions and cognition is a substantial management problem under any circumstances, and even with volunteers, more professional care and training will be needed.

To this end, direct support for mental health care and training is desperately needed, particularly for community-based programs and particularly indeed in programs designed to prevent IV needle transmission and among professionals caring for those patients.

For clinical management there's only a modest literature on the management of the neuropsychiatric aspects of the disease. We clearly need more individual and group counseling and psychotherapy, community and family care as well as much improved knowledge of medication, which can help us help the patient.

Further, many patients have the need for a support-structured environment outside of the hospital. The appropriation of funds for mental health research related to these issues, I think, should be a priority. I understand that the House has provided such support. The studies of the impact of emotions on the immune system is a major issue and this needs to be explicated—I think the area is, I think it's psychoneuroimmunology. And we have some early data but clearly not enough.

I'd like to add a final note, a major change in the nature of the AIDS epidemic, I think, exists in the emergence of new antiviral drug for management of the disease.

Exciting as this is though, a note of caution is much in order. We need to be deeply concerned lest we are seeing the paradox of success. We should learn from our gains with other diseases, first acute, now chronic, that often as we extend life we increase dependency but with little or no support for the ongoing care needed for the now chronically ill individuals. Long-term care is a major problem in the United States

and I'm embarrassed to say this but I believe it has been the orphan child of health care policy.

I almost put another word in rather than orphan. It has not been something that we should be proud of in this country, Mr. Chairman.

If indeed it is the case that in AIDS we are potentially creating a chronic disease out of an acute one, it must be noted that the current modes of care, primarily acute hospitals and clinics, reliance on volunteers, on hospice for terminally ill and informal support, which works well enough for acute time-limited episodic intervention, may be unable to sustain us in caring for a much enlarged chronically ill, multiply diseased, AIDS population. We need rapidly to initiate innovative programs to address the problem of a spectrum of supportive arrangements, particularly in view of the data that a substantial number, if not the majority of AIDS patients, died living alone. Thus families may not be readily available to supply the needed care and support to this group, as for example they are with many frail elderly. Progress involving support of housing, long-term home health care such as for example the program of the Lombardi program in New York State, educational programs, case management and support for family volunteers and professionals who care for patients is desperately needed.

In summary, Mr. Chairman, the need for more clinical research into behavioral, emotional, and neuropsychiatric aspects of disease should be a high priority. Support for direct mental health services and for services involving long-term care need to be initiated and they need to be initiated, I would contend, as expeditiously as possible.

I commend you on holding this hearing, Mr. Chairman, and your concern with this tragic and critical problem, thank you.

Senator CHILES. Thank you.

Dr. Parks.

STATEMENT OF WADE PARKS

Dr. PARKS. Good morning. By way of personal background, I am a medical virologist. I have a Ph.D. in virology and I am also a physician certified by the American Boards of Pediatrics and Allergy and Clinical Immunology. I am head of the division of immunology and infectious disease and the department of pediatrics at the University of Miami School of Medicine. In that capacity I direct a laboratory-based research program in pediatrics AIDS at Jackson. We are currently funded by a number of peer-reviewed NIH, National Institutes of Health grants for the conduct of our research. My knowledge and appreciation of the Federal prospective of issues related to AIDS derives in part from 8 years of service in the Public Health Service with the National Cancer Institute and my current position on an NIH study section that reviews grants related to epidemiology and disease control. Also I'm chairman of the virology committee within the AIDS treatment and evaluation units and in that capacity direct 19 different laboratories in virology nationwide.

Time does not allow a review of our research interests. You will have heard much of this from others. But what I would like to address today is a topic that has been ignored for so long that I think it's bound to have a serious impact on the consequences for the conquest of AIDS as well as other important biomedical issues. This topic is research space.

My logic proceeds as follows: First, money allocated for care and treatment must not be allowed to overwhelm dollars spent for research.

Second, money for AIDS research must consider issues of space necessary for the accomplishment of this research.

Third, Federal dollars are urgently needed for research space construction.

The remainder of my presentation will detail some of these.

From the point of view of one trained in infectious diseases, there is little that is specifically unique in AIDS, except quantitatively. Similar problems have existed before, we have had yellow fever and syphilis earlier in the century which medical science dealt with, albeit slowly. More recently, we have had situations like swine flu that we want to avoid and cancer where we have still not succeeded. Since my personal legacy draws heavily from polio, let's consider briefly the management of poliomyelitis research. Parents' fears about polio in their children was no less in the 1940's and 1950's than parents today about AIDS. If anything it was perhaps more, if I had to guess. Dollars available at that time through the March of Dimes were divided roughly equally for care and treatment and for research. That balance still seems appropriate today for AIDS, but my prediction is that the balance will be imperiled as health care needs increase in the future. Care and treatment dollars will potentially dwarf research dollars. We know the medical needs, we care for babies with AIDS. We're not insensitive. I argue for and have great need for care and treatment dollars to manage our patient responsibilities.

However, such dollars are akin to buying iron lungs for polio patients. We must be careful to avoid excessive expenditures that do not ultimately result in control and elimination of AIDS worldwide. In my opinion, we will achieve control over AIDS—as we have over poliomyelitis, measles, mumps, and German measles in just the past 25 years—only though it be balanced between research funding and care and treatment expenditures are properly balanced. I know the drama of ill patients. Spending money to pay for patient care is always safe, but in a public health sense, ultimately unproductive. We must strive to do what is best for the most. As unglamourous as it is, my point of view is that research space is the most underfunded aspect of AIDS today.

The second topic is space for AIDS research. At the University of Miami, in 5 years, AIDS funding as you indicated in your opening remarks, has grown to the point where it accounts for 25 percent of our total sponsored program support. Overall, in the past 2 years alone, our research budget has increased 50 percent. Yet there's been no new research space construction in 15 years. Space to do research is the major limiting factor for AIDS research at our university and also nationwide.

In fact, space is the most precious commodity for all research at the university. We have a saying, to do research you need three things, money, people, and space. Well, we have the first two as you indicated, but we don't have the space. Without research space, University of Miami scientists and scientists nationwide will not make their maximal contribution to the control of AIDS. We are not alone in this regard.

Where will the space come from? The private sector? In spite of a highly successful $400 million fundraising campaign by the University of Miami, space for AIDS will not derive from that campaign. Because of public perceptions, the nature of contributions, previous commitments, nonconstruction needs, et cetera, the private sector will not provide money for AIDS research space. What about the Government? The State of Florida has generously supplied funds to the University of Miami, $150,000 for laboratory enhancement which required in part construction of a containment laboratory and they've also provided over $4 million for care and treatment space. Do you see why I am concerned about imbalances also in expenditures? The State alone will not provide research space construction. What then about the Federal Government?

There is no Federal money appropriated for construction of AIDS research space. There is no significant mechanism for construction dollar expenditure. Frankly, from my perspective, NIH is not primarily interested in academic research space needs. What about Congress? This year's House budget contains zero dollars for research facilities construction. Senator Dodd's National Science Foundation Reauthorization Act only contains $143 million to be spread over 3 years. These are hardly adequate in view of the needs. An independently funded study by Dr. Armand Hammer and the American Cancer Society for the need for cancer research facilities estimated that cancer alone requires $1.3 to $2 billion in order to reach what they needed. A copy of that report was distributed to the staff this morning. So who will pay?

This brings us to the third part of my presentation, the need for Federal support for research space construction and renovation. Historically, American biomedical science call to light in this century with the advent of laboratory based or scientific medicine. After World War II, the funding of the National Institutes of Health and the construction of research facilities laid the foundation for American Medical science. It Was the 1960's and early 1970's that the construction dollars for research facilities were made available. Since then, dollars for construction have all but disappeared. The speaker at my medical school graduation in 1967 and recipient at that time of an honorary degree was Senator Lister Hill, from Alabama. The Hill-Burton matching fund provided much of the academic research space that we have available today. We need a Senator Hill in AIDS research. I think that private and State funds would match Federal dollars to build AIDS research space. Regardless, it is apparent that Federal dollars for research facility construction are the only dollars that can impact in a timely fashion for AIDS. If we start now, we can construct research facilities that will shorten the time necessary to control AIDS.

Thank you for your consideration.

PREPARED STATEMENTS

Senator CHILES. Thank you, very much.

I thank each of you for you testimony and it's all tremendously important and sort of overwhelming to me.

[The statements follow:]

Statement of Wade Parks

Good morning. By way of my personal background, I am a medical virologist. I have a Ph.D. in Virology and I am a physician certified by the American Boards of Pediatrics and Clinical Immunology and Allergy. I am the head of the Division of Immunology and Infectious Disease in the Department of Pediatrics at the University of Miami School of Medicine and in that capacity I am responsible for AIDS in the Department of Pediatrics at Jackson Memorial Hospital in Miami. I have been awarded several honors in relationship to my research and am currently funded by a number of peer reviewed grants from the National Institutes of Health for the conduct of our research in AIDS. My knowledge and appreciation of the Federal side of these issues derives from eight years with the National Cancer Institute during the heyday of the Virus Cancer Program from 1970-77 and from my present service on an NIH Study Section that reviews grants related to Epidemiology and Disease Control. Currently, I am also associated with the AIDS Treatment and Evaluation Units within the NIH as a member of the National Drug Selection Committee for the AIDS Treatment and Evaluation Units, serve on the ATEU Steering Committee and serve as chairman for the Virology Program within the AIDS Treatment and Evaluation Units. This latter program directs and monitors the virology carried out within nineteen virology laboratories in the ATEU. My curriculum vitae further details my background.

At the University of Miami, our particular research interest has been the description of AIDS in children. Dr. Gwen Scott and myself were the first to describe in detail the natural history of the infection in children; this was reported several years ago in the New England Journal of Medicine and then again with Dr. Scott and Fischl, we described the presence of severe immunologic abnormalities which ended in frank AIDS in the mothers of children with AIDS; this was published three years ago in the Journal of the American Medical Association. These studies have lead subsequently to a number of other clinical and basic science publications concerning pediatric AIDS and the virus that causes this disease.

In the course of this research, we have identified several <u>novel</u> aspects of the research problems associated with AIDS. Such findings are to be expected, but are largely unpredicatable before one becomes involved. It is a characteristic of research to find new questions. Similarly, the history of research in infectious diseases is mirrored in AIDS. Briefly, there is nothing unique about AIDS as an infectious disease that has not already been described earlier in other diseases. However, there are particular problems in AIDS research that now require solutions and have not previously been resolved. These include immunity to viruses such as influenza, control of sexually transmitted diseases and numerous fundamental basic science questions. To effect the same control of AIDS as we have been fortunate to achieve with other viral diseases such as polio, measles and rubella in the past fifty years, it will be essential to find answers to these specific problems of the AIDS virus.

Our research into the virology, chemotherapy, immunology and vaccinology of AIDS all began as a result of <u>local initiatives</u> at the University of Miami. These initiatives were taken in response to our perception of relevant problems and needs. These local initiatives have paralleled, complemented, been funded by, but more often have guided national initiatives in the areas of pediatric AIDS and heterosexual AIDS virus transmission. Research efforts in Florida, other parts of the United States and France, reflect the importance of investigator-initiated initiatives in academic research in the study and eventual control of human diseases such as AIDS. It is my opinion that the balance of academic, industrial and federal efforts have often been misinterpreted by governmental agencies and by the public. This is in part illustrated by the perception of needs for research space.

There is currently no federal initiative for research space to do AIDS research.

Before addressing that topic specifically, let me broadly indicate those research issues of current importance at the University of Miami. You will have heard of other emphases this morning and by way of positive reinforcement and documentation, I have submitted separately the recommendations for research made by the National Academy of Sciences. The areas of research that we presently perceive as most important relate to the interruption of transmission of the virus from one person to another. As we have learned more regarding person to person transmission, it is clear that the best prevention of transmission is immunologic protection akin to that achieved through vaccines. Normally, vaccines are predicated on a complete understanding of the natural history of a given disease. Through natural history, we learn where to place the emphasis of our efforts. In the case of AIDS, there are a number of potential points in chains of transmission where it is possible to interrupt transmission. Obviously, in children we feel that it may be possible to interrupt transmission from mothers to children at the time of birth. Since the AIDS virus is predominantly transmitted by sexual means in adults, it may be possible to vaccinate individuals who are in frequent contact with infected sexual contacts. Another approach is through the use of drugs such as AZT to reduce the amount of virus present in infected individuals so that they are less likely to transmit virus. Each of these models has important precedents. For example, the interruption of perinatal transmission is routine today for hepatitis B through the use of vaccines and immune serum globulin. The use of drugs such as AZT in chemoprophylaxis is akin to the use of isoniazide to prevent the transmission of tuberculosis. Realizing the cost of the AIDS epidemic and the low socioeconomic status of many infected people, there is obviously a place for governmental support for drug and vaccine purchases. This type of government support has ample precedents.

In order to achieve the results already obtained and to extend these AIDS research efforts in academic settings, several new things are necessary. In our own institution, as well as at several other centers, the major problem is the availability of laboratory and clinical research space. Overall, the University of Miami research programs have increased over fifty percent in the last two years alone in terms of sponsored program support. Yet, there has been almost no significant new construction for the last fifteen years! Currently, space is the most precious commodity in our setting and the need is great for new space, not only to replace outdated space designs and outdated equipment, but to provide new space to accomodate medical research growth. This growth is not only in the area of AIDS but also in other areas. In fact, AIDS has massively altered the academic balance in our center. I have distributed reports concerning research at the University of Miami School of Medicine. Our situation is not atypical of other academic centers involved heavily in AIDS research. Funding for AIDS research now constitutes over 25% of the sponsored research budget and over a third of the indirect cost recovery that the University of Miami uses to administer this research. Thus, AIDS has resulted in a significant amount of money for the University, but what may not be appreciated is that this money also puts an enormous burden on a University to provide services necessary for the proper expenditure of AIDS grant money. Thus AIDS may impact negatively on other academic efforts in the short term.

It is ironic that money is spent for research yet there is nothing for space. There is no federal mechanism to provide for construction. Where will work be done? Already the absence of space has caused significant problems for a number of AIDS-related programs at the University of Miami. The absence of new space will result in an inability to make our maximal contribution to progams to control AIDS. Whereas the South Florida

community has been extremely generous in the provision of funds for a $400 million dollar fund raising campaign at the University of Miami, these dollars are not all immediately available nor are they all targeted for construction, nor even for biomedical research. Nor are there specific plans for AIDS research space. So even if the money from Miami's $400 million dollar effort were available today, it would have less than sufficient impact on the specific AIDS space needs. In order to develop a full scale effort to study AIDS in the next two to five years, it will be necessary to start immediately on space needs and construction plans. In my opinion, it is an urgent problem.

Since medical research is one of the only businesses that tries to put itself out of business, it is unfortunate that there is too little space to accomplish this. The Senator(s) will appreciate more than most people that the availability of Hill-Burton funding for medical school research construction in the 1960's was the source of much of our nation's present worldwide strength in biomedical research. Since that time there has been little or no federal funding in this area. One continually hears that funding at the federal level for research construction remains one of the lowest priorities. The House, for example, this year has zero dollars in its appropriations for biomedical construction. Perhaps we should examine how this is so - in fact, this anti-construction attitude has a long history in this country. It is an attitude that I would argue is short-sighted.

It is hard to believe that less than one hundred years ago laboratories were not an integral part of American medical schools. In 1886, when William Henry Welch left Bellview Medical College in New York City, to become the first Dean at Johns Hopkins Medical School in Baltimore, one of his major inducements was the willingness of his recruiters at Johns Hopkins to construct a building exclusively for his laboratories. Attempts to keep him in New York City, included a commitment to convert the hospital's ice cream parlor into space for Welch's laboratory work. Laboratories were then a totally new concept. Even today, laboratory based clinical research (precisely what is needed to stop AIDS) remains a novel idea for most medical schools. What is accepted is that laboratories are essential for basic science departments.

It was not until after the Second World War with the founding of our National Institutes of Health, that significant growth in scientific medicine was appreciated. With Lister Hill's and others' efforts at the federal level, space for medical research was developed in such a way as to make our national biomedical research efforts the envy of the world. Today, that position is threatened somewhat by France, Germany and particularly Japan. Money and specifically, money for space is one of the keys to maintain our position. Today we are faced with the same situation that existed at the end of the 19th century. As it relates to virology, the problems of availability of laboratory space for the conduct of medical research is in a serious state. It is my opinion that we can not continue to ignore this fact. Further, to expect local initiatives alone to provide these important national resources is impractical. Even Senator Dodd's proposed $143 million dollars for laboratory refurbishment through NSF over three years is woefully insuffient in my opinion and does nothing to address the specific needs for AIDS research space.

AIDS is but one example, albeit a most important one, that reflects the lack of available space for the conduct of research. There are, in my opinion, a large enough number of individuals who are qualified to do important work on AIDS, but the problem is to bring them together in settings where there is adequate appropriately designed space. At the present time, even if money existed for construction, the University of

Miami is two to three years away from such an optimal space situation. On the other hand, such a facility, if constructed, would be a center of excellence in research that would make significant contributions to the vaccinology and the delivery of the protection against the spread of AIDS at a worldwide level. And this is a worldwide disease.

In conclusion, it should be noted that to deal with the problem of AIDS on a worldwide scale reinforces the vaccine approach and not drugs. The vaccine effort is just beginning. AIDS will have a profound impact on the world situation, not just in third world countries, but everywhere. AIDS has become one of the major events of our lifetime, but we should not allow it to be larger than necessary for the lack of space to do research.

Thank you for your attention.

Statement of Gwendolyn B. Scott

Since the first case reports of AIDS in children in 1983, the numbers have increased steadily. As of July 27, 1987, The Center for Disease Control had received reports of 551 cases of AIDS in children under 13 years of age. The majority of these cases (78%) were due to perinatal transmission, i.e. from an infected mother to her infant. However, this number grossly underestimates the actual number of infected children since there is a broad spectrum of clinical illness associated with HIV infection in children and only the children with more severe illness meet the definition for AIDS and are reportable cases. Thus in our experience, for every one child reported with AIDS there are at least two or more children who are clinically symptomatic but do not meet the criteria for the diagnosis of AIDS. An additional 153 cases are reported nationally in the 13 to 18 year age group. As of July 1, 1987, our state of Florida had reported 2,606 cases of AIDS. Sixty-four cases were in children under 13 years of age and fourteen were between the ages of 13 and 19. In Miami, we have diagnosed 170 HIV infected children at our medical center between January, 1981 and July 1987. Of these, only 54 meet the criteria for the diagnosis of AIDS. At the present time we are actively following about 90 infected children. almost all of these children are identified as infected because of the presence of clinical disease. It is not known how many children have infection but are asymptomatic.

In children under 13 years of age, the majority of infection occurs as a result of perinatal transmission. An infected mother may transmit

the virus to her infant across the placenta during pregnancy, at the time of delivery, or postnatally by ingestion of infected breast milk. Other causes of infection in this age group are blood or blood product transfusions from an infected donor. In the 13 to 18 age group, the causes of infection are more similar to those in adults. Approximately 48% are homosexual or bisexual males, 22% have hemophilia or a coagulation disorder, 6% are from blood transfusion, 6% from drug abuse, and 3% from heterosexual contact.

Cases of AIDS in children are reported from 34 states, the District of Columbia and Puerto Rico, but the majority reside in one of four states, New York, Florida, New Jersey and California. AIDS is generally a disease of metropolitan areas and the majority of cases are reported from New York, Miami and Newark. In children, this illness is common in those living in the inner city who come from low socioeconomic backgrounds. Recent national statistics, show that 54% of children are Black, 25 % are Hispanic, and 21 % Caucasian. It is estimated that about 70 % of these cases can be related to drug abuse in one of the parents.

HIV infection in children is largely a disease of infants and toddlers. Over 80% are diagnosed in children under 3 years of age and the majority of children present with clinical illness in the first two years of life. There are a few children who do not develop clinical illness until after age 3, but these are in the minority. Overall, the sex distribution in children is equal. Unfortunately, the prognosis is grim. The proportion of children with AIDS who die is high and national statistics suggest that once a child is diagnosed with AIDS, the median survival is less than one year. The majority of deaths in this illness occur in the first two years of life. There are a few children with long term survival, but many of these eventually develop disease and have significant morbidity and mortality despite longer survival.

The disease in children differs from that in adults. For instance, Kaposi's sarcoma in children in rare, whereas it is common in HIV

infected adult males. Also, between 30 and 50% of children develop a lung condition called lymphoid interstitial pneumonitis which is uncommon in adults. Such differences stress the importance of studying the natural history of this disease in children. Also, the diagnosis of disease in infants is more difficult because mother passes gamma globulin containing antibodies across the placenta before birth. If the mother is seropositive to HIV then the baby's serum will also contain antibody to HIV. This is called passive transfer of maternal antibody. However, early in life we cannot tell whether this represents actual infection in the infant, or only passive transfer of antibody from mother to infant. Therefore, antibody testing alone cannot determine whether or not an infant is infected. In some cases this maternal antibody may persist for several months and the child's HIV status may not be able to be determined until 15 or 18 months of age. A definitive diagnosis of HIV infection under 15 months of age can only be determined by the presence of clinical illness, a positive virus culture, or a positive antigen test. Research efforts need to be directed toward the development of simple laboratory tests for diagnosis in the child less than 15 months of age.

From this information, it is clear that if children are to be saved from the devastation of this disease, infected children must be identified early, preferably before the onset of significant clinical symptoms and treated. At present, Phase 1 treatment protocols with both Ribovirin and Azidothymidine (AZT) are underway in children with clinical illness. Results of these trials are preliminary. Drug studies in children have lagged behind those in adults but the urgency to gather information on drugs and move into Phase II treatment trials is no less urgent. It is also important to gain more information about when and how the infection occurs in perinatal transmission. If infants are infected while still in the uterus, then perhaps even treatment at birth will not be effective and antiviral drug treatment should be evaluated in infected women who choose to carry their pregnancy to term in an attempt to prevent disease in their newborn. If the infection occurs at the time of delivery from exposure of the infant to bloody secretions, then an approach similar to that used in

evention of Hepatitis B in infants might be helpful--i.e. to give perimmune globulin (high titered antibody against the infecting ent) in this case HIV, in an effort to prevent infection. This uld then be combined with a vaccine when available to hopefully otect against disease transmitted through infected body secretions the time of delivery. This approach has been very successful in eventing hepatitis B infection in newborns born to women who carry e hepatitis B infectious antigen particle in their blood. Thus, forts toward the development of high titered antibody to HIV for use post exposure prophylaxis should be supported. The newborn pulation is also an ideal population to target for early vaccine ials.

addition, new drugs must be made available to children as soon as fety is established so that efficacious drugs will be available for eatment of infected children as well as adults. Since many of these ildren will come from families who are poor and cannot afford the st of drugs, it is important that these drugs be made generally ailable so all children have an equal chance for treatment. This ll likely require a large allocation of funds to pay for these eatments. Priority should also be given to the development and inical trials of new antiviral drugs.

e of the keys to control of this disease in infants and young ildren, is to prevent disease in women. Presently the ratio of male females in the United states infected with AIDS is about 15:1 wever over the past year the greatest percent increase in number of ses has occurred in females. As of July 27, 1987, 2914 women had en reported with AIDS. If the number of asymptomatic cases of HIV fection in females is similar to that in males, there may be up to more times this number infected, but not clinically ill. These nen are in the child bearing age group and the majority are Black or spanic. In our experience with perinatal AIDS, the majority of nen are asymptomatic at the time of delivery of their first infant th AIDS. The infant is frequently the first member of the family

identified as having HIV infection. In order to deal with this epidemic it is important that women know their HIV status,--to provide the best medical care for themselves as well as to make educated choices about becoming pregnant and having an infant. It is estimated that about 30 to 50% of infants born to HIV positive mothers will be infected. This is a significant risk. Thus, I think it is important to provide testing and counselling in settings such as family planning clinics, prepartum clinics and at the time of delivery. This would provide the pediatrician an opportunity to identify a child at risk early and provide better medical care for this child. Also, as treatments become available then testing and identification of infected infants will become crucial so they can be placed on treatment protocols early.

As stated earlier, the mode of transmission in perinatal disease is not well established. More research is needed in this area. If most of the disease occurs early in gestation then it is logical that women who are HIV positive should be treated with antiviral drugs that are safe to use during pregnancy to prevent infection in the fetus. If the disease occurs at the time of delivery then a model similar to hepatitis B preventation in the infant might be utilized ie, high titered antibody plus vaccine. In the case of HIV infection, the use of high titered HIV antibody plus antiviral drugs or when available, HIV vaccine. Transmission of the virus via breastfeeding has not been studied extensively, but the virus has been cultured from a small number of specimens of breast milk and there is one case that is convincing for transmission of the virus by breastmilk to an infant. This mother was infected just after delivery by a transfusion. She breastfed her infant and seventeen months later both mother and infant were found to be infected with HIV. We do not know whether breast milk from all infected mothers in all stages of disease can transmit the virus. More research is needed in this area, since breast milk is essential in many parts of the world for survival. It is unknown what the incremental risk of infection is if a mother who is HIV positive breastfeeds her infant.

Lastly, I would mention the adolescent age group--generally an ignored group but in the context of AIDS--an important one. The mode of transmission in this group is more similar to adults, ie IV drug abuse, sexual transmission, both homosexual and heterosexual, and the remainder from infected blood or blood products. We have no idea how many adolescents might be infected--even in areas of high prevalence. This is a group where education is essential and they must be aware of how this disease is transmitted. To my knowlege there are few program and no research targeted toward this group. It would be important to obtain baseline data regarding incidence of HIV positivity in adolescents and college students. It is important to learn how to educate this group, and not only adolescents in high school but also college students should be targeted for major educational efforts. They must be aware of how they can protect themselves.

In closing my recommmendations will generally be directed toward women and pediatric populations including adolescents.

1) There should be continued support for study of the natural history of this disease in infants and children as well as the prospective followup of infants born to HIV positive women to determine what proportion of infants will be infected.

2) To better understand the pathophysiology of disease in children, additional funds need to be allocated for the study of organ specific diseases such as: encephalopathy and developmental disabilities in children, cardiac involvement and pulmonary disease especially lymphoid interstitial pneumonitis.

3) Support for studies of perinatal transmission including maternal factors which may promote transmission from mother to infant, as well

as mechanisms of in utero transmission. In addition, studies of the role of breast milk in transmission are important. Basic information as to whether the virus is present in breast milk from women in various stages of disease is not available. We also do not know what role specific antibodies in the breast milk play in protection from HIV if the infant is breastfed. The incremental risk to the infant for developing infection if mother is HIV positive and breastfeeds her infant has not been determined.

4) Additional support should be provided for the development of new diagnostic techniques for detection of infection in newborn infants.

5) Support for development of new antiviral drugs is crucial. Drug studies need to be instituted early in children. Treatment programs should be targeted to prevention or modification of disease in newborn infants by treatment of the HIV positive pregnant female or the newborn infant.

6) Funds need to be allocated to provide treatment for all HIV infected individuals.

7) Development of other potential therapies, such as high titered HIV antibody preparations, should be supported.

8) Vaccine development should be a priority.

9) Support for development of model programs for education and counselling for families with HIV infection.

10) Support for education programs targeted to school children, adolescents, and women with regard to HIV infection and protecting oneself.

STATEMENT OF CARL EISDORFER

Mr. Chairman, distinguished members of the committee, I am Carl Eisdorfer, Professor and Chairman of the Department of Psychiatry at the University of Miami and Professor of Psychology. I am also the Director of the University's Bio-Psychosocial Center for the Study of AIDS which is funded by a competitive grant from the National Institute of Mental Health (NIMH) and jointly with the National Institute of Drug Abuse (NIDA). I hold the M.D. and Ph.D. degrees. My focus in this testimony will be on the Neuropsychiatric Aspects of AIDS. A more complete understanding of the neuropsychiatric aspects of AIDS is emerging slowly, but the significance of mastering the behavioral, emotional and cognitive aspects of HIV infection and its subsequent pathophysiology should not be underestimated. Our efforts at understanding the virology and immunology of the infection, and efforts at immunization and treatment must, in anything, be increased. However as we come to understand the spectrum of disorders associated with HIV spread we should also recognize that understanding the behavioral and neuropsychiatric issues can play a major role in patient care as well as in managing disease spread.

May and Anderson (Nature, March 1987) describing mathematical modelling of the transmission dynamics of HIV reminds us of a salient point. AIDS is transmitted by specific types of behavior and its spread is affected by both the carrier phenomenon and the degree of heterogeneity in sexual activity as well as IV drug use.

It should not go unstated that the minimal early efforts to address this lethal problem were likely influenced by the concentration of the disease among male homosexuals and associated attitudes toward what may have been perceived as a

marginal group engaging in behavior not condoned by the dominant majority. The more recent spread among IV drug abusers and prostitutes perhaps involves a similar reaction. It is, of course, important to note that after active concern with the safety of blood, the behavior, sexual and otherwise, of homosexual men, IV drug abusers, prostitutes and individuals of particular geographic origins, we are now concerned with the sexual practices of all individuals. AIDS, then, from its inception fits the model not of a single infectious disorder with a simplistic host-organism relationship, but of a biopsychosocial disorder best understood not only in the context of its etiology but also the individual's reaction to that etiologic agent, the consequences of that reaction and the mediating factors involved in the course of the infection and disease. Simply put, stress on the community and individual plays a role in the dynamics of the disease.

I will not dwell here on many of the elements of the concept of stress except to say that stress does have a negative effect on the immune system of the individual as well as on the emotions. My focus here is to address the more clinical aspects of the HIV/AIDS progression as it appears neuropsychiatrically and its public health implications.

Persons at high risk for AIDS include not only gay men, prostitutes, intravenous drug users, and persons living in areas of high geographic density of infected individuals, but also newborns of infected mothers and sexually active individuals of both sexes who are involved with multiple partners. Many adults at risk, even whole communities, may join what has been described as the "worried well." I've had numerous interviews with gay men and others who have stated that the illness and death of their friends, the lack of any vaccine, the risk of loss of employment or disclosure, family upset and the rest -- reactions familiar to this group -- have led them to avoid testing. In response to the query, "What are you feeling?", the answers range from

frightened, sad, anxious, to I try not to think about it or frank anger at what is seen as society's reaction to this situation.

It is often those who are frightened who come for testing and many undergo a period of considerable anxiety until the test data are available to them. Some get so anxious that they don't return for the test results. Before and certainly during this period, support and counseling are key and psychosocial interventions are important at this period.

In our laboratories, we are studying the value of counseling as well as physical exercise programs and other psychosocial mediators to help mediate the consequences of testing and feedback. The role that this early mediation may play in the progression of the infection must await more time for the studies to be completed.

In the presence of HIV infection, individuals often exhibit the symptoms of anxiety and distress. Uncertainty and fear about the eventual outcome of their condition, pressure to alter their intimate personal and sexual behavior which in the past probably had a supportive effect for them and fear of disclosure which could cause them a host of repercussions from loss of friends to loss of employment are only a few of the problems they encounter. Often we see a high bodily concern about any physical change and the symptoms of a depression with sadness, guilt, lowered self-esteem, suicidal ruminations and suicide. Depression, in turn, is often associated with an increased sense of isolation which in some instances is associated with the actual reduced support of individuals formerly closely associated with the infected person. Holland and others have pointed out that the literature on terminal cancer patients is relevant to these individuals and even more to those who develop an AIDS-related complex or AIDS itself. Denial and anger often directed toward those caring for them is not unusual. In addition in AIDS, cognitive problems, including forgetfulness and slowing of thinking are frequently voiced complaints.

AIDS dementia has now become an issue of major concern for caregivers. The early view of the progression of AIDS dementia, prior to about 18 months ago, was that the HIV-infected individual developed AIDS or AIDS Related Complex (ARC), and in the face of diminished immunocompetence would develop a secondary central nervous system infection. These secondary disorders, most frequently toxoplasmosis, lymphoma or CMV, usually caused psychopathology in the form of dementia and schizophreniform behavior. In instances, such secondary CNS disorders may be treatable. Behavioral disturbances also may occur secondary to Pneumocystis carinii or any of a host of physical disorders which occur secondary to the collapse of the immune system.

About a year and a half ago, reports were published which pointed out that the HIV directly infected the brain even in advanced changes in the blood which characterizes AIDS as a disease. This affinity of the virus for the higher central nervous system is now a well recognized phenomenon and the clinical consequences quite profound.

The features of primary AIDS dementia involve an insidious onset, occasioned by a rapidly accelerated pace in the absence of a concurrent systemic disorder. In one study, global mental deterioration leading to significant dementia was noted in one-half of the patients within two months while one-half manifested moderate dementia then deteriorated rapidly after four to seven months. Forgetfulness, mental slowing, poor concentration, apathy, social withdrawal and motor symptoms, particularly balance, were problems in about half of the patients early on. In infants with AIDS, all show developmental lags.

Reactive psychiatric disturbance is also likely to stem from pre-existing personality states. Many individuals will be overwhelmed by the profound threat of AIDS or, secondarily, to the physical disruption caused by the secondary disease state. The mediators of these NP disturbances are the premorbid state,

the nature of the medical problem and the psychosocial supports available to the individual.

The most frequent problems in psychiatry appear to be adjustment disorders, depression, delirium (often relative to the management of the patient), and cognitive deficits, eventually global dementia.

It should be noted that while depression may be a psychological reaction to the devastating illness confronted by the patient, there exists also the possibility that depressive affect may be an early manifestation of the alterations in the higher CNS very much as has been demonstrated for the symptoms of depression in left-sided strokes.

Perhaps simplistically, we can characterize AIDS patients as showing a set of neuropsychiatric disturbances which can be characterized mnemonically by four D's: denial; depression; delirium, and dementia, and the patient can have various combinations of these problems. Treatment of each of these could be undertaken symptomatically and by addressing the underlying condition. Patients with "denial" constitute a particular problem in that their behavior as patients makes management difficult and their behavior as social individuals makes them a problem in efforts to contain the disease spread. The "delirious" patient shows signs which have been labelled schizophrenic or schizophreniform with delusions and hallucinations, and of course this, too, creates a major medical management problem. The "depressed" patient is often a suicidal risk, and we all need to be alerted to this problem, particularly in view of recent data, attendant speculation and publicity as to the proportion of HIV positives who will become AIDS patients over the longer time frame. "Depression" probably also adversely influences the immune system.

Later stages involve severe global impairment and significant psychomotor retardation in the majority of patients. The exact nature of the brain involvement is not entirely

explicated. What is clear, however, is that there has emerged a dementia syndrome with specific properties now being described neuropsychologically and neuropsychiatrically.

Jaffe and his colleagues at NIMH have presented data that "depression" may be an important risk factor for the development of AIDS among HIV-infected individuals. Though the data are scant, they also pointed out that in subjects without neurologic signs slowing occurs on a number of psychological tests. Speed functions and visuospatial problems seem a particular problem among those without focal lesions.

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I would now like to focus on staff issues. I cannot say enough about caring for the caregivers who, provide the care for the complex patients -- facing the inevitability of death and reactions to loss. Those dealing primarily with the infections or cancers are often hard pressed to cope with the neuropsychiatric aspects of patient care as well. Add to this the perceived risk of possible personal infection and the behavior of patients whose psychiatric problems may make them unpleasant to deal with and the issue becomes more acute. The role of family and volunteers also requires special note. Volunteers from the gay community have worked with great effect in many settings. I have heard well informed estimates that well over 100,000 hours of volunteer time was donated in the San Francisco community. But the IV drug user, that group perhaps most isolated and among the socially most marginal is a far more difficult individual to support and understanding the social and ethnographic patterns of the users is important in helping caregivers in dealing with these patients. Volunteers from the gay community may feel considerably less enthusiasm as the population base of AIDS patients becomes more heterogenous, and other groups are not stepping forward in cities around the country to address this growing problem.

Simply put, relying on volunteers is a bad way to plan for future clinical needs. The patient with impaired emotions and cognition is a substantial management problem under any circumstances and even with volunteers, more professional care is needed.

Support for staff is a well studied technique for improving morale, staff retention and improved functioning through preventing burnout, yet there is little or no financial help for this activity since reimbursement is usually tied to direct patient services.

For clinical management there is only a modest literature on the management of depression, anxiety and schizophreniform behavior associated with AIDS. We desperately need more individual and group psychotherapy, community and family care as well as knowledge of psychotropic medication which can be of great value, helping the patient, caregivers and community deal with the home based problems related to the disease which again is often not supported. For example in dementia, the environment can be an important issue: the role of supportive housing, orienting devices such as clocks and calendars, signage consistency staff training, not overloading patients with information or orders but insuring that instructions are remembered, use of carefully written materials balancing stimulation with level of cognition, the role of visitors, etc. In short, these patients have a need for a supportive structured environment in or hopefully out of the hospital. This also includes homemaker services.

We must be careful about psychotropic medications since these patients often have CNS problems and more research is needed to help us manage the impaired patient.

At this time, a major change in the nature of the AIDS epidemic is the emergence of new anti-viral drugs for management of the disease. AZT now approved for use is doubtless only the first, and early anecdotal reports are that it has a desirable

effect on dementia. Large scale studies have as yet not given us the data we need to understand whether the improvement noted was that of secondary cognitive change to systemic disease or whether it has more direct CNS action. However, it looks promising.

Exciting as this is, though, a note of caution is very much in order. We need to be deeply concerned lest we are seeing the "paradox of success." We should learn from our gains with other diseases that now become chronic illnesses often we extend life at the expense of increased dependency and inability to carry out the activities of daily living - but with little or no support for the ongoing care needed. Long-term caring is a major problem in the U.S.

The recent initiative in catastrophic illness under Medicare still makes no provision for the substantial number of individuals requiring ongoing nursing home or daily home based care. If indeed it is in the AIDS case that we are creating a chronic disease out of an acute one, it should be noted that the current modes of care, focussing on acute hospital and clinic; volunteer, hospice and informal support, which works well for acute time-limited episodic intervention will be unable to sustain us in caring for a much enlarged, chronically ill AIDS population. We need to address the problem of a spectrum of supportive caring arrangements, particularly in view of data that the majority of AIDS patients live alone. Thus families may not be readily available to provide needed care and support to this needy group. Progress involving supportive housing, long term home health care such as the Lombardi program in New York State, community educational programs, case management and support for those family volunteers and professionals caring for patients is desperately needed. The need for clinical research into the psychological and neuropsychiatric aspects of the disease is increasingly apparent. Direct mental health services are desperately needed and there is no apparent resource for much of this type of care.

In closing, let me be another member of the chorus that pleads for more research into the disease and its manifestations with a particular focus on its biopsychosocial interactions, its emotional and behavioral components and its clinical management.

Senator CHILES. It's certainly, Dr. Scott, a sad fact that we have the second highest rate of children with AIDS here in Florida and you tell me we don't now know anything about how that's transmitted and whether we can prevent some of that transmission. And if the mothers don't even know until the child shows up with AIDS, basically that they were, that they were patients, that's all sort of overwhelming to me, to tell you the truth. I can't get my mind about it and thinking about these children, that the innocent, most innocent of the innocent, you know, that they are the victims of this thing.

Dr. SCOTT. Well, I think that's why we feel that pediatric AIDS is so important because it has served as the index for identification of infected men and women and other children within the family. And I think in terms of attempting to prevent further cases of pediatric AIDS, the key really does lie in women, and it's very important, I feel, that women be aware of their HIV status.

Senator CHILES. Let me ask you this, you know we keep talking and skirting around this question of testing and how we get the testing and voluntary and mandatory and everything. Would you advise any pregnant prospective mother to be tested?

Dr. SCOTT. I think certainly, certainly women who live in areas where there is a significant incidence of AIDS I would feel that hospitals and agencies should offer voluntary testing for those women and that should be followed up with counseling with regard to the results, whether it be positive or negative, because they also need to know how to avoid AIDS.

Senator CHILES. Well, that gets into Dr. Eisdorfer's field and he certainly makes a great case for the need for that counseling.

Again, trying to get my mind around where all of these dollars are going to come from, where we're talking about—and we're recognizing that we do deal with limited dollars, it would be nice if we didn't, but we do that, so we do have that problem, and where do we try to put the emphasis? Certainly we know that trying to do something in this infant thing is terribly important. Targeting those populations where we know that they're greatest at risk for the education and it certainly seems that we've got to do that and then of course you both, you all, each make such a case for the area in which you're talking about. And as I say, I continue to be concerned that the dollars that we do put in we spend most effectively and that we try to get the most for them and especially for stopping the future spread of this terrible disease and yet trying to treat humanely these people that have it at the time.

Well, I have some other questions. Our time is just such that we need to kind of move but—and I again want to stay in touch with you and

through our staff as we are trying to put together our budget figures in this regard. And we thank you very, very much for your work you're doing and your testimony today. It's terribly important.

STATEMENTS OF:

SALLY DODDS, ACSH, EXECUTIVE DIRECTOR, HEALTH CRISIS NETWORK, INC.

FATHER FRED TONDALO, P.S.J., EXECUTIVE DIRECTOR, CENTER ONE, ANYONE IN DISTRESS, INC.

LOUIS MAX, LCSW, PROJECT DIRECTOR, COMPREHENSIVE AIDS PROGRAM OF PALM BEACH COUNTY, INC.

LINDA S. QUICK, EXECUTIVE DIRECTOR, HEALTH COUNCIL OF SOUTH FLORIDA, INC.

Senator CHILES. Next, our last panel of experts work in the area of providing medical support for AIDS patients. Our panel includes Sally Dodds, who's the director of the Health Crisis Network [HCN] and then Fred Tondalo, executive director of Center One and Louis Max, project director of the Comprehensive AIDS Program.

Miss Dodds, we'll start off with your testimony this morning.

Ms. DODDS. Thank you, Senator. My name is Sally Dodds and I'm the executive director for Health Crisis Network, Inc.

Health Crisis Network is the only agency in Dade County exclusively devoted to the problems presented by the AIDS epidemic. HCN sprang from its grassroots in early 1983 when an immunologist from the University of Miami began seeing an increasing number of persons with AIDS in her practice. Incorporated later that year, HCN literally ran out of the trunks of people's cars, staffed by volunteers until mid-1985. Now in just 2 years, the demands of the service agency have pushed this organization to being the second largest in the Southeastern United States.

Without reiterating much of what was already said to you, that our needs are urgent; a public sector catastrophic health plan must be developed to meet not only necessary medical costs, but costs that are usually unsupported or less supported such as experimental drug therapies, residential care, and home health and psychosocial services.

That funding for education and prevention efforts needs to be made available to the communities directly from the sponsoring Federal agency, not only channeled through State and local public health departments.

And that individuals at risk, or infected by the virus, need to be protected from discrimination.

Thank you.

Senator CHILES. Thank you, very much.

STATEMENT OF LOUIS MAX

Mr. MAX. Yes; I'm Louis Max, project director of the Comprehensive AIDS Program of Palm Beach County.

First I want to thank you all for the opportunity of giving testimony reflecting our experience in this county.

e Comprehensive AIDS Program of Palm Beach County, which is ed in part by the Robert Wood Johnson Foundation, has a twofold ose. On the one hand we have a community-based home health care management initiative of registered nurses, social workers, cer- l nurses aides, and homemakers, who deliver care within the home onment in order to maintain the person with AIDS or ARC at e as long as possible, delaying or avoiding altogether the need for italization or nursing home placement. In some cases, as you know, iates of the daily costs of hospitalization and treatment of a person AIDS range upward of $1,000. However, utilization of home care essionals, augmented by volunteer assistance, dramatically reduces for care. Home care provides persons with AIDS and their families individualized and personalized care in a familiar environment e to family and friends. So simply stated, at the Comprehensive S Program, we feel that everyone does better at home. Maintaining ons in their own home environment places responsibility where it ld be placed, upon family, loved ones, churches, and other com- ity-based resources.

my own experience, I can present countless examples in which lies with support from our professional staff and volunteers have onded admirably and lovingly to family members affected with S. Some family members have even expressed profuse thanks for privilege of being able to care for a child, a mother, a wife, a d, for the opportunity to learn so much about themselves and for chance to be drawn closer to their loved one as often happens when e is illness and crisis. Institutionalization and hospitalization, they're a necessary part of the entire spectrum of care for the person with S. can serve to distance and separate, to let us all off rather too and to enable us as families, friends, and neighbors to shirk the responsibility we must have toward one another.

might add, furthermore, that the medicare model of home health, its stringent requirements such as homebound status, intermittent specific rather than holistic interventions, productivity levels, ed social work visits, and so forth—all part of Health Care Finan- Administration guidelines, will not appropriately meet the demands ersons with AIDS [PWA's] and their families in this epidemic. er a new model of care, such as we are attempting in Palm Beach nty, needs to be explored. This model includes an adaptation to particular environment and population. For example, in Palm h County, our population urban as well as suburban and rural, in- ng migrant workers, a variety of ethnic and cultural groups, the in- minority, nonminority populations, gay white males, with a er percentage of minorities, females, and entire families infected by S. Our client population, moreover, is spread over a large sprawling raphic area. Indeed, because of the unique demographics of Palm h County we had to split our program into two teams yet we were nitted to maintain high professional quality and standards within We've had to attract indigenous—this is particularly in the Glades

area, indigenous people represent that community—to represent the profiles of both the western part of the county, including the Glades area, as well as the eastern coastal areas. In addition, because some of our social service supports remain thin and spotty, we've had to build up resources as well as to educate professionals within the social service agencies to the unique demands of caring for persons with AIDS. Consequently, our professionals have needed to take more time visiting in the home because of additional ancillary needs such as family education. In many instances, as has been alluded to earlier about people dying alone and living alone, the CAP staff is the only person a person with AIDS sees during the week, particularly in the Glades area.

Our program rather reverts to an earlier time in which the professional visitor was a generalist and a one-person community resource. In many cases, at the Comprehensive AIDS Program [CAP], our emphasis has been on strengthening existing family structures and supporting these families through home health professional support, volunteers, church assistance, and other community resources.

So in Palm Beach County, our model has had to be organic, based on our own population, and within that population we've had to respond to the varigated flavor that is Palm Beach County.

In like manner, the CAP program has also mounted a campaign of education and information which parallels our home care effort in that it adapts to the unique qualities of Palm Beach County. For example, part of our client load involves Haitian persons who have an entirely different attitude toward disease and illness. Disease means something different to a Haitian person than it does to a person from the United States. We have had to educate health care professionals, law enforcement personnel, educators, religious leaders, as well as persons within the private sector about AIDS prevention. Through alliance with the PWA coalition of Palm Beach County, we are assisting in the empowerment of the group most affected and most vulnerable. It is our firm belief that PWA's must have a voice their own health care as well as legislative issues which affect them so deeply.

So in short what we're calling for:

One, an assertive national policy with clean goals and objectives, setting a tone emphasizing antidiscrimination, psychosocial, and community support. Though the policy may be formulated nationally, allowances must be made for local needs. This approach must be comprehensive, proceeding simultaneously on the front of prevention, treatment, and research.

In addition, No. 2, we're calling for Federal funding of professional programming which is locally controlled and which responds to the unique needs of each locale, emphasizing in-home supportive and community-based care, housing, out-patient clinics, and hospitalization. Direct service programming and education must relate to the unique social and ethnic flavor of each community.

But also calling for a concentrated, coordinated national initiative to search out and make available all treatments for AIDS. In addition. it is

our feeling that we must not remain tied to an orthodox medical model, but rather we must explore all alternative therapies on behalf of our clients.

Four, we are calling for legislative safeguards to protect the civil rights of persons with AIDS and families in the provision of services, housing, insurance, dental care. employment, as well as military service.

And incidentally, it's a good opportunity here to say that there's been something of a holdup in SSI eligibility which is supposed to be expedited. It's taken people up to 6 months to become eligible for supposedly an expedited program.

We feel any discrimination would serve to force affected persons underground which would isolate these persons from public health assistance and from all attempts to arrest the spread of the epidemic.

And I want to thank you again for the opportunity to present this testimony and to make known our own needs here in the county.

Senator CHILES. Thank you, sir.

Father Tondalo?

STATEMENT OF FRED TONDALO

Father TONDALO. Yes, sir; my name is Father Fred Tondalo, an Orthodox Catholic priest with the Poor Servants of Jesus. I'm also an executive director of Center One, Anyone in Distress, Broward County's only AIDS service agency.

As the AIDS crisis grows more serious we are going to be faced in the United States with a challenge which will test the very fiber of our character as a Nation. The pain and suffering of those with AIDS and the enormous tragedy for the families, loved ones, and communities of people with AIDS cries out for loving, compassionate, and efficient response. Diversionary and destructive emotional reaction will not compliment our character as a Nation nor as a people. Neither will such reactions serve anyone save the horrible objectives of the virus itself.

Practically speaking, the U.S. Government, knowing slowly but surely that the problem will not disappear by itself, must look with new vision to the overwhelming needs this disease will present and to approaches which may not have been considered in the past.

The problems most acute, in my opinion, are care and treatment which includes symptom management, out-patient services, expanded hospice care, home health care, and psychosocial support systems and not only services. By systems I mean a continuum of intervention to support an individual, not only occasionally but on a regular basis. This can be accomplished, as we at Center One have demonstrated in Broward County, by utilizing large numbers of volunteers under staff supervision.

By utilizing volunteers, local grassroot agencies can manage large numbers of patients for far less cost and much higher effectiveness than bureaucratic institutional programs.

My recommendation is that the Federal Government consider funding agencies like Center One which, I believe, could effectively and efficiently serve the nonmedical needs of people with AIDS.

There are very serious problems in managing a person with AIDS socially. Isolation and rejection are commonplace, causing simple problems to escalate into major crises because of a lack of ability on the part of the patient to either feel able to or to be physically able to reach out for help.

By utilizing voluntarism with adequate staff assistance, including professional social workers and therapists, tremendous savings can be realized as well as quality care given.

We must begin to change the stigma which we have placed on those afflicted with AIDS. To change the perception of AIDS from a punishment to an infection and those afflicted with AIDS as the problem to a virus as the problem. To change our response from finger pointing to one of an open hand ready and willing to raise one up from the darkness of fear and persecution into the light of our love and compassion for anyone who suffers.

This is the response we give to Ethiopian famine victims, will we do less for those who suffer as much from AIDS for our own citizens?

If I could just digress from my written comments for a moment and give my opinion about creating new monuments or, if I could use the phrase, Vatican Cities surrounding AIDS care and treatment and research. I think that we need to be very, very careful with how we spend the limited resources that we are going to need to expend and as was aptly stated before in testimony, that our productivity as a Nation is going to be affected very severely by this crisis. And we think we need to look at new models for saving those resources and also delivering the quality care that we need to deliver to those people.

Thank you.

Senator CHILES. Thank you, sir.

Ms. Quick?

STATEMENT OF LINDA S. QUICK

Ms. QUICK. Thank you, Senator Chiles.

I'm Linda Quick. I'm executive director of the Health Council of South Florida and the staff director of the relatively new South Florida AIDS Advisory Committee.

Senator Chiles, I want to start perhaps by thanking you for your leadership in a variety of health and human services issues that the health council has been involved with in its nearly 20-year history. And I want you to know that we in Florida particularly appreciate and note your efforts in everything from infant mortality to long-term care for the Nation's elderly. Even your unsuccessful efforts to save the nationwide health planning system is greatly appreciated by this organization and this community.

I'd have to say also, because I'm an honest person, that I'm a little disappointed that other members of your committee were unable to join you today but I am sure that you will articulately share with them what you've heard during this testimony.

Senator CHILES. Hopefully many of them are doing something in their States and trying to get information as well.

Ms. QUICK. I hope so.

PREPARED STATEMENTS

I'd like to depart from the written testimony that I submitted to you today and take the unusual opportunity of being last in your schedule to perhaps underscore and highlight and occasionally supplement——

Senator CHILES. Your written statement will be included, each of you, in the record.

[The statement follows:]

Statement of Sally Dodds

Senator Chiles, members of the Committee, my name is Sally Dodds, and I am the Executive Director of Health Crisis Network, Inc. Health Crisis Network (HCN) is the only agency in Dade County exclusively devoted to problems presented by the AIDS epidemic. HCN sprang from its grassroots in early 1983 when an immunologist from the University of Miami began seeing an increasing number of persons with AIDS in her practice. She, along with a social worker from another community medical center began running a support group for these patients, meeting weekly in their homes. Some 12 persons with AIDS participated in that first support group, and within 6 months, all but two had died. It was clear at that point that there needed to be an organization capable of meeting the needs of individuals and their families and loved ones experiencing this devastating illness. Thus, Health Crisis Network was born. Incorporated in October of that year, HCN literally ran out of the trunks of peoples' cars, staffed by concerned citizens volunteering their time and talents until mid- 1985. Community contributions enabled HCN to rent a single room on the second floor of a church in a low income section of Miami, and install a single telephone to serve as an AIDS "hot line." Soon, space for a second room was negotiated, and a regular support group began. Some clients were literally carried up and down the steps in their wheelchairs. These same volunteers began making educational presentations to groups at high risk for some attempt at prevention. In two years, the demands of the epidemic has pushed this grassroots, volunteer organization into the second largest AIDS-service organization in the southeastern United States. Fifteen, full-time staff, and over 225 active volunteers are now responsible for several comprehensive programs:

A. CLINICAL SERVICE

HCN's Clinical Service department currently provides psychosocial counseling and support services to nearly 350 persons with some degree of HIV infection and their families/loved ones. The agency has had a cumulative number of clients of over 800. It is difficult to portray the depth of despair for all persons along the spectrum of infection, for the disease is one of rapid wasting and progressive deterioration until death. Our counseling services, to individuals, families and groups is aimed at crisis intervention and crisis management, adjustment and adaptation to catastrophic illness and disability, and death and dying counseling. Referrals are made to appropriate community resources such as food stamps, Social Security, etc. A grant from the United Way of Dade has allowed HCN to develop a model, case management program with the Visiting Nurse Association and Hospice, Inc., to coordinate home health and hospice services to people terminally ill with AIDS. We provide transportation to and from doctor's appointments and other necessary services. Chore services, such as homemaking and grocery-shopping are provided by volunteers, as are social and recreational activities to reduce loneliness and isolation. We provide emergency food and, on a limited basis, emergency financial assistance. The spiritual needs, so vital in dying persons, are attended to by trained, volunteer clergy from all denominations. And, for legal services, HCN's volunteer attorneys work on a pro bono basis for people unable to afford legal counsel.

B. EDUCATIONAL SERVICES

Educational Services about AIDS are divided into two major divisions - training and technical assistance (to health and mental health providers, educators, and others), and education for prevention (to individuals, groups and communities at highest risk, as well as to lower risk groups.) Training some 1500 people in workshops and seminars each month, we find that education is a highly complex

process, and that it must be repeated frequently. Further, education about AIDS must be delivered in ways that will be received by intended audiences. Specific terms that describe the behaviors that transmit the virus must be sensitive, precise, relevant and indeed, sometimes graphic. Within this context, special attention must be given to racial, ethnic and sexual minorities of a region, and the unique attitudes and values of each. To meet this need, HCN has developed several task forces to help guide us in the development of educational materials and approaches that will best be received by Miami's diverse community - one each for hispanics, Haitians, American blacks, gay men of all racial and ethnic heritages, drug treatment personnel, and women. These task forces are best able to provide the outreach necessary to indigenous populations.

C. INFORMATION AND REFERRAL

By far, the single largest component of Information and Referral at HCN are its "hot lines." We currently have four hot lines, including one for non-English speaking people and one 800 number for out-of-area callers. Hot lines serve a variety of functions in AIDS, from information about transmission of the virus, to referral to knowlegable clinics and physicians for diagnostic evaluation or for antibody testing, to crisis intervention for suicidal callers. HCN's hot line staff and volunteers respond to over 1500 incoming calls each month. It is significant to note that the types of calls have changed dramatically over the two years of the Hot Line's operation. Startlingly, we are moving away from the preponderance of calls being from an ill-informed public about such concerns as the safety of eating in restaurants, to an increase in crisis calls, even to the point of suicide. At HCN, we can only infer that the widespread use of HIV testing without adequate pre- and post-test counseling is contributing to this change - in the past two and a half months, we have received 7 calls from people who received positive HIV test results, and who killed themselves between the time they called, and the time when they were scheduled to see a counselor. For one young woman, this was but a 4-hour time span. All of these callers had received testing, with the standard pre- and post-test counseling, from such reputable places as the Alternative Test Site run by the Public Health Department and the American Red Cross. As a result, we at HCN have now instituted procedures whereby <u>all</u> callers (and clients), who have recently learned of HIV positivity are handled as high risk for suicide.

D. VOLUNTEER SERVICES

HCN, like so many other AIDS-service organizations around the country, was born of the the volunteer initiative of concerned citizens, primarily gay. At HCN, there are currently over 225 active volunteers, men and women, gay and non-gay, retired adults and high school students who contribute over 1300 hours of service each month. These compassionate and concerned individuals work directly with clients and their families, provide transportation, cover the hot lines, provide clerical support, raise funds and so much more. The value of volunteerism goes far deeper that just the concern shown by these dedicated individuals. Economically, at an estimated rate of $5.50 per hour, these volunteers contribute nearly $7,000 each month. This figure does not reflect the fact that a great many of these volunteers are physicians, nurses, attorneys, psychologists and other professionals whose time is really to be valued at a much higher rate. And, for those volunteers who themselves are members of high risk groups, the education and support they receive from peers

about changing behaviors that spread virus, the benefit of their contribution is extraordinary, not only to the agency, but to the entire community.

It is significant to note that at the mid-point in HCN's fiscal year, only 19% of the agency's income came from grants and contracts from public sources. The rest came from the generosity of concerned citizens in the community, the majority of which are its gay citizens. Despite this fact, HCN is committed to providing services to all persons affected by the AIDS epidemic regardless of racial, ethnic or sexual minority status, and regardless of financial resources. A very important factor that guides HCN's commitment to outreaching sub populations is, that unlike the other major epicenters of the AIDS epidemic, South Florida is a laboratory of diverse populations. This factor underscores the necessity of creating programs for AIDS in the US that respond to the uniquenesses of each community. Further, 3/4 of all of Florida's cases are located within the contiguous southern counties of Palm Beach, Broward, Dade and Monroe. This fact speaks to the necessity of regional AIDS program planning to share resources of an already overburdened health care system. By knowing our region, we can plot nearly parallel epidemics - the ever transient migrant worker following the crops and moving between the agricultural areas of Homestead and Florida City in the south, through Miami's Little Haiti and on to the fields of Belle Glade to the north; following the sun, gay men move between the beaches of Ft. Lauderdale, Miami Beach and Key West, and, throughout the region, often among gay men and migrant workers are men and women who sell and use illegal drugs, some shooting them into their veins, others bargaining their bodies for money to purchase crack cocaine. The risks of most of these people extend to their unborn children as well.

Despite Florida's high ranking nationally, and probably due to a relatively small number of AIDS cases in the early days of the epidemic, we were a bit slow on the uptake in meeting the challenges posed by AIDS. It was not until 1985, when then Governor Bob Graham appointed a state-wide Governor's Task Force on AIDS, did we begin an appropriate course of action for the State of Florida. Simultaneously, the Health Council of South Florida convened a body of some 150 people to create a documented plan for action in four primary areas - research and prevention, care and treatment, information and education and legal and ethical issues. The recommendations of the Governor's Task Force, the plan developed by the Health Council, funds provided by the Florida legislature, the federal government, private foundations, and the volunteer initiative of concerned citizens have enabled Florida to make some notable progress in the war against AIDS.

Probably most notable are the model demonstration programs of South Florida about AIDS that are being adjusted, then duplicated to other Florida communities, as well as to the rest of the nation. Our planning documents have been widely disseminated. The research capabilities of the University of Miami School of Medicine, the Veteran's Administration Medical Center, and Mt. Sinai Medical Center cover a broad range of basic science, clinical and biopsychosocial research projects. The South Florida AIDs Network, based at Jackson Memorial Hospital, is developing a unique, responsive model of care and treatment on an inpatient, outpatient and community basis. Community philanthropathy, under the auspices of the United Way of Dade, funds a demonstration project for home health care for AIDS patients. Additionally, 30 skilled nursing home beds are under development at the Dade County Human Resources Health Center. And still, our services are woefully inadequate. The initial budgets for this care and treatment project were developed with the goal of providing care to approximately 300 patients. However, during the period between October 1986 and April 1987, over 1,000 persons with HIV infection have been served.

As for community education efforts, CARE - the consortium for AIDS-related education - includes representatives from the Dade County Public health Department, HRS, Dade County Schools, The University of Miami, Health Crisis Network, Miami-Dade Community College and others. Though this group has been meeting for months, and has identified targets and strategies for educational intervention, we have been unsuccessful in finding adequate resources to carry out educational programs to the extent necessary to prevent the spread of infection.

One word I've used consistently throughout this statement is "community." In Dade County, we have strategically emphasized the concept of community in all of our planning and program development. Effective service delivery cannot be done without the full participation of community members. At all levels, we have sought out leaders and organizations from all of our affected sub-communities, provided them resources and enhanced their programs in the ways they have directed. We know that people ill with AIDS live at home, in the community, and thus our care and treatment program stresses the less costly, and more comfortable alternatives to lengthy hospitalization. We know that behavior change is best accomplished when education and information is reinforced by family, friends and community norms, and thus our educational programs stress the use of indigenous workers in neighborhoods and communities. And, we know that Miami is not like San Francisco or New York or Dayton, Ohio, and though we can learn from the experiences of others, we must understand our AIDS epidemic to best meet our needs.

As we fast approach a decade of knowing AIDS in this country, it is important that we start from a common perception of the problems we face:

1. We are in the grips of a major, worldwide pandemic that is caused by a virus that is entirely new to the human race;

2. The USPHS estimates that for every one reported case of fully diagnosed AIDS, there are 50 more people infected with the virus, and that the virus is being transmitted as we speak here today;

3. That the longer a person carries the infection, the more likely that he/she will develop the full-blown disease (some longitudinal studies are beginning to indicate that 35%, possibly as many as 90% of persons infected with the virus will actually become ill). Patients die from AIDS-related complex. We are beginning to understand that the virus affects the central nervous system long before it becomes evident in the immune system. They appear as old men with Altzheimer's Disease, losing their vision as well as their memory. All along this spectrum of disease, people with HIV infection begin to consume health care at an ever increasing rate;

4. That although science is rapidly developing a promising armamentarium of experimental drugs, AIDS is always fatal. And, for those individuals fortunate enough to have the body chemistry that will allow for the use of some of these promising experimental drugs, they are frequently denied access because of the prohibitive cost of the drug. AZT therapy, a substance that allows many AIDS patients to regain strength and even return to work costs roughly $10,000 per patient per year. As a result, a dangerous backlash of "guerilla" clinics and laboratories have emerged, selling unusual mixtures of vitamins, eggs and other substances to desperate people. This problem not withstanding, we are learning that with good medical intervention and psychosocial support, some AIDS patients are living longer as disabled people, rather than as immediately being terminally ill. For many, with responsive and flexible employers, gainful employment can be maintained;

5. That AIDS knows no gender, no sexual preference, no race or ethnicity, and no age;

6. That AIDS is costly: to science for the necessary biomedical research; to already strained health care as patients consume its resources in their progressive, painful deterioration; and to society, as fully 90% of people dying of AIDS do so in the prime of their working years (between the ages of 20 - 49);

7. That AIDS can be prevented. Today is not the time to avoid our responsibility for accurate and specific information by hiding behind traditional values. AIDS futures demand that we reach our young people openly and honestly, that we confront our fears with massive, state of the art education.

Our needs are urgent:

1. It is urgent that a public sector catastrophic health plan be developed to meet not only necessary medical costs, but costs that are usually unsupported or less-supported, such as experimental drug therapies, residential care and home health and psychosocial services, and that eligibility determination for such programs be rapid and easily accessible;
2. We urgently need funding for education and prevention efforts that are made available to communities directly from the sponsoring federal agency, and not only channeled through state and local public health departments who often have competing priorities and restrictive implementation guidelines;
3. We urgently ask that additional funding be made flexible to respond to unique community needs. Field initiated requests are a highly complementary strategy to federally-conceived plans and programs;
4. It is urgent that individuals at risk, or infected by the virus, be protected from discrimination. Losses of employment, insurance, residence and school placement are real occurrences in the lives of people with AIDS-related problems. Fear of ostracism and public disclosure drives people underground, away from being vital participants in public health surveillance programs, educational efforts, and research;
5. It is urgent that we honestly face the many underlying social problems that are the true cofactors of the spread of AIDS: poverty, racism, homophobia, drug abuse and others.

June Osborn, MD, Dean of the School of Public Health at the University of Michigan, has well identified our challenge: the ways we meet this epidemic will indeed dictate the way that we meet the next. Surely, there will be another.

Statement of Father Fred Tondalo

AS THE AIDS CRISIS GROWS MORE SERIOUS WE ARE FACED, IN THE UNITED STATES, WITH A CHALLENGE WHICH WILL TEST THE VERY FIBRE OF OUR CHARACTER AS A NATION.

THE PAIN AND SUFFERING OF THOSE WITH AIDS AND THE ENORMOUS TRAGEDY FOR THE FAMILIES, LOVED ONES AND THE COMMUNITIES OF PEOPLE WITH AIDS, CRIES OUT FOR LOVING, COMPASSIONATE AND EFFICIENT RESPONSE.

DIVERSIONARY AND DESTRUCTIVE EMOTIONAL REACTION WILL NOT COMPLIMENT OUR CHARACTER AS A NATION NOR AS A PEOPLE. NEITHER WILL SUCH REACTION SERVE ANYONE SAVE THE HORRIBLE OBJECTIVES OF THE VIRUS ITSELF.

PRACTICALLY, THE UNITED STATES GOVERNMENT, KNOWING SLOWLY BUT SURELY THAT THE PROBLEM WILL NOT DISAPPEAR BY ITSELF, MUST LOOK WITH NEW VISION TO THE OVERWHELMING NEEDS THIS DISEASE WILL PRESENT AND TO APPROACHES WHICH MAY NOT HAVE BEEN CONSIDERED IN THE PAST.

THE PROBLEM MOST ACCUTE, IN MY OPINION, ARE CARE AND TREATMENT, WHICH INCLUDE [illegible], HOME HEALTH CARE, AND PSYCHO-SOCIAL SUPPORT SYSTEMS NOT ONLY SERVICES. BY SYSTEMS I MEAN A CONTINUUM OF INTERVENTION TO SUPPORT AN INDIVIDUAL, NOT ONLY OCCASIONALLY, BUT ON A REGULAR BASIS. THIS CAN BE ACCOMPLISHED, AS WE AT CENTER ONE HAVE DEMONSTRATED IN BROWARD COUNTY, BY UTILIZING LARGE NUMBERS OF VOLUNTEERS UNDER STAFF SUPERVISION. (DETAILS OF SPECIFIC PROGRAMS ARE OBTAINED IN THE INFORMATION PACKETS YOU HAVE RECEIVED.)

BY UTILIZING VOLUNTEERS, LOCAL GRASS-ROOT AGENCIES CAN MANAGE LARGE NUMBERS OF PATIENTS FOR FAR LESS COST AND MUCH HIGHER EFFECTIVENESS THAN BUREAUCRATIC INSTITUTIONAL STYLE PROGRAMS.

MY RECOMMENDATION IS THAT THE FEDERAL GOVERNMENT CONSIDER FUNDING AGENCIES LIKE CENTER ONE WHICH, I BELIEVE, COULD EFFECTIVELY AND EFFICIENTLY SERVE THE NON-MEDICAL NEEDS OF PEOPLE WITH AIDS.

THERE ARE VERY SERIOUS PROBLEMS IN MANAGING A PERSON WITH AIDS SOCIALLY. ISOLATION AND REJECTION ARE COMMONPLACE, CAUSING SIMPLE PROBLEMS TO ESCALATE INTO MAJOR CRISIS BECAUSE OF A LACK OF ABILITY ON THE PART OF THE PATIENT TO FEEL ABLE TO OR TO BE PHYSICALLY ABLE TO REACH OUT FOR HELP.

BY UTILIZING VOLUNTEERISM WITH ADEQUATE STAFF ASSISTANCE INCLUDING PROFESSIONAL SOCIAL WORKERS AND THERAPISTS TREMENDOUS SAVINGS CAN BE REALIZED AS WELL AS QUALITY CARE GIVEN.

WE MUST BEGIN TO CHANGE THE STIGMA WHICH WE HAVE PLACED ON THOSE AFFLICTED WITH AIDS. TO CHANGE THE PERCEPTION OF AIDS FROM A PUNISHMENT TO AN INFECTION, AND THOSE AFFLICTED WITH AIDS AS THE PROBLEM TO A VIRUS AS THE PROBLEM. TO CHANGE OUR RESPONSE FROM FINGER POINTING TO ONE OF AN OPEN HAND READY AND WILLING TO RAISE ONE UP FROM THE DARKNESS OF FEAR, AND PERSECUTION INTO THE LIGHT OF OUR LOVE AND COMPASSION FOR ANYONE WHO SUFFERS.

THIS IS THE RESPONSE WE GIVE TO ETHIOPIAN FAMINE VICTIMS.-- WILL WE DO LESS FOR THOSE WHO SUFFER AS MUCH FROM AIDS WHO ARE OUR CITIZENS?

Statement of Louis Max

The Comprehensive AIDS Program of Palm Beach County, funded in part by the Robert Wood Johnson Foundation, has a two-fold purpose: on the one hand, we have a community-based, home care initiative of registered nurses, social workers, certified nurses aides, and homemakers, who deliver care within the home environment in order to maintain the Person with AIDS/ARC at home as long as possible, delaying or avoiding altogether the need for hospitalization or nursing home placement. In some cases, estimates of the daily costs of hospitalization and treatment of a person with AIDS range upwards of $1000. However, utilization of home care professionals, augmented by volunteer assistance, dramatically reduces costs for care. Home care provides PWA's and their families with individualized and personalized care in a familiar environment close to family and friends. Simply stated,

at the Comprehensive AIDS Program we feel that everyone does better at home. Maintaining persons in their own home places responsibility where it should be placed - upon family, loved ones, churches, and other community-based resources.

In my own experience, I can present countless examples in which families with support from our professional staff and volunteers have responded admirably and lovingly to family members affected with AIDS. Some family members have even expressed profuse thanks for the privilege of being able to care for a child, a mother, a wife, a friend, for the opportunity to learn so much about themselves and for the chance to be drawn closer to their loved one as often happens when there is illness and crisis. Institutionalization and hospitalization, though often a necessary part of the entire spectrum of care for the PWA, can serve to distance and separate, to let us all off rather too easily, to enable us as families, friends, and neighbors, to shirk the deep responsibility we must have toward one another.

I might add, furthermore, that the Medicare model of home health, with its stringent requirements, such as homebound status, intermittent care, specific, rather than holistic, intervention, productivity levels, limited social work visits, and so forth - all part of HCFA guidelines, will not appropriately meet the needs of PWA's and their families in this epidemic. Rather a new model of care, such as we are attempting in Palm Beach County, needs to be explored. This model includes an adaptation to each particular environment and population. For example, in Palm Beach County, our population is urban, suburban,

and rural, including migrant workers, a variety of ethnic and cultural groups, the indigent minority, non-minority populations, gay white males, with a higher percentage of females and entire families affected by AIDS. Our client population, moreover, is spread over a large, sprawling geographic area. Indeed, because of the unique demographics of Palm Beach County, we had to split our program into two teams, yet we were committed to maintain high professional quality and standards within both. We had to attract local, indigenous professionals to represent the profiles of both the western part of the County, including the Glades area, as well as the eastern, Coastal areas. In addition, because some of our social service supports remain thin and spotty, we had to build up resources as well as to educate professionals within the social service agencies to the unique demands of caring for persons with AIDS. Consequently, our professionals have needed to take more time visiting in the home because of additional and ancillary needs, such as family education. Our program rather reverts to an earlier time in which the professional visitor was a generalist and a one person community resource. In many cases, at the Comprehensive AIDS Program our emphasis has been on strengthening existing family structures and supporting these families through home health professional support, volunteers, church assistance, and other community resources.

Therefore, our model has has to be organic, based on our own population and within that population, responding to the variegated flavor that is Palm Beach County.

In like manner, the CAP program has also mounted a campaign of education and information which parallels our home care effort in that it adapts to the unique qualities of Palm Beach County. For example, part of our client load involves Haitian persons, who have an entirely different attitude towards disease and illness. We have had to educate health care professionals, law enforcement personnel, educators, religious leaders, as well as persons within the private sector about AIDS prevention. Through alliance with the PWA coalition of Palm Beach County, we are assisting in the empowerment of the group most affected and most vulnerable. It is our belief that PWA's must have a voice in their own health care as well as legislative issues which affect them so deeply.

We are calling for:

1. An assertive, National policy with clear goals and objectives, setting a tone emphasizing anti-discrimination, psychosocial, and community support. Though the policy may be formulated nationally, allowances must be made for local needs. This approach must be comprehensive, proceeding simultaniously on the fronts of prevention, treatment, and research.

2. Federal funding of professional programming which is locally controlled and which responds to the unique needs of each locale, emphasizing in-home supportive and community-based care, housing, outpatient clinics, and hospitalization.

Direct service programming and education must relate to the unique social and ethnic flavor of each community.

3. A concentrated, coordinated National initiative to search out and make available all treatments for AIDS. In addition, it is our feeling that we must not remain tied to an orthodox, medical model, but rather we must explore all alternative therapies on behalf of our clients.

4. Legislative safeguards to protect the civil rights of PWA's and families in the provision of services, housing, insurance, dental care, employment, as well as military service. Any discrimination would serve to force affected persons "underground," which would isolate these persons from public health assistance and from all attempts to arrest the spread of the epidemic.

Statement of Linda S. Quick

Acquired Immune Deficiency Syndrome (AIDS) has been called the nation's major public health problem. The state of Florida ranks third behind New York and California in the number of reported AIDS cases. By the end of 1991, it has been projected that there will be between 30,000-50,000 cases of AIDS reported in the state. As the number of AIDS cases increases there will be a dramatic increase in the number of AIDS Related Complex (ARC) cases and Human Immunodeficiency Virus (HIV) infected individuals. As the number of cases increases so will the demand for services. With estimated hospital costs of an average $140,000 per patient, the funding of services for this population cannot be overlooked. Without adequate alternatives to inpatient care, hospital costs will continue to increase. Additionally, education and prevention efforts are essential if a decrease in the spread of the Human Immunodeficiency Virus is to be attained. Increased funding for research efforts is also needed. We call upon the legislature to take decisive action on a number of public health and personal privacy issues as it deliberates proposals regarding AIDS. Such legislative efforts should address the following:

- A network of community services must be available and accessible to persons with AIDS related conditions. Legislation developed should support the creation of local networks to include out-patient ambulatory services, residential shelters, mental health services, home health care and long term care.

- Efforts should be made to eliminate existing barriers to proper care, specifically those found to residential care such as adult congregate living facilities (ACLF), long term care services such as nursing homes. This can be accomplished through special licensing requirements, requirements for education, and improved reimbursement mechanisms. For the purposes of this policy. ACLF's shall include adult group homes and foster homes.

- Finding a cure or vaccine for AIDS will require further research. Consequently there must be continued resources earmarked for research purposes.

- Education is the only tool available at the present time for the prevention of the spread of the Human Immunodeficiency virus. Educational efforts should be expanded and targeted to all individuals whose behavior places them at risk for AIDS, including the general public. We support the Surgeon General recommendations for education of children.

- Voluntary, confidential or anonymous testing, especially among high risk groups, should be encouraged. Counseling, to include pre-test counseling, and support services must be available for those who test negative/positive for HIV infection to assist them with the psychological impact of the infection and making decisions about appropriate lifestyle change. Ensuring confidentiality is extremely important and must be enforced to the utmost.

- Pre-employment testing provides no useful results and only increases the anxiety about the disease, therefore mandatory serological testing of individuals should be discouraged.

- Legislation should be developed that prohibits the isolation or restriction of persons with AIDS, ARC or who have tested positive for antibodies, in the educational and work settings that do not involve the handling of infected bodily fluids.

- There has been evidence to show that persons having tested positive for the AIDS virus are being excluded from eligibility to health insurance programs. We ask that legislation be passed to make it illegal for insurance companies to terminate a person with a diagnosis of AIDS or AIDS related conditions under the context of a pre-existing condition. Also, we support legislation that prohibit the testing of individuals as a pre-requisite for insurance coverage.

- Legislation developed must be designed to reflect responsibly the findings and recommendations of the Center for Disease control with the respect to work place and employment policies.

- Legislation must be passed to address the issues of liability insurance coverage and limits for those agencies and their staff who provide services to persons with AIDS.

- Legislation must be passed to address the issue of Communicability of AIDS and the licensing of Adult Congregate living facilities as housing has become a major problem for this client population.

- We ask for continued legislative support for comprehensive AIDS Funding to include additional monies for alcohol, Drug Abuse and Mental Health programs.

- Aids has adversely affected minority populations, therefore we ask for special Funding for AIDS education that will address these specific groups with consideration given to ethnic and cultural diversity.

HEALTH COUNCIL OF SOUTH FLORIDA

The Health Council of South Florida, Inc. is a voluntary, not-for-profit corporation serving Dade and Monroe Counties in Florida. The Councils' purpose is to provide effective health planning for the area and to promote development of health services, manpower, and facilities which meet identified health needs in a cost effective manner. Our Agency has provided this Kind of leadership in South Florida since 1968.
In October 1985, the Health Council of South Florida began a massive and concentrated effort to assist Florida in their efforts to address the impact of Aids.

Initially, the Health Council Board of Directors authorized the establishment of an Ad Hoc Committee on AIDS to develop a plan. The Committee, with 35 members, was an effort to assure representation and participation from affected parties, political and social leadership, and those segments of the health care community actively involved in South Florida AIDS efforts. Nearly 50 people were put on the interested party list, receiving notices of meetings and offered an opportunity to participate. The first three meetings were spent on orientation, education and issue clarification. The plan chapters and content areas were selected. The Ad Hoc Committee members and interested parties were asked to serve on four work groups identified earlier by the full Ad Hoc Committee and representing chapters in the plan: public education and information; care and treatment; legal and ethical dilemmas; research and prevention. Discussions were lively and emotions often high as the struggle for priorities, direction and exactness of expression took place at workgroup meetings. Surely, completing and preparing the written plan for full Committee and ultimate Council adoption belies the effort and emotional energy committed to the planning process.

The planning process and the plan that resulted in April of 1986 was not complete. AIDS is a dynamic disease and does not lend itself to absolutes.

Even as the 150 people engaged in the plan development process asked questions, studied the issues and available data - new reports were being published, new treatments being persued, and unfortunately new cases were being diagnosed. In the year that followed many positive things have also happened and the Health Council of South Florida is proud to continue being an active participant in these plan "implementation" process as well.

Most importantly and in a large part as a result of congressional actions,the care and treatment portion of the plan is currently being implemented. In Dade County, this effort is characterized by the South Florida AIDS Network - a federation of service providers centered and administered through the University of Miami Medical School/Jackson Memorial Hospital,with participation from Visiting Nurses Association, Hospice, Health Crisis Network, Dade County's Human Resources Health Center (nursing home), Florida Department of Health and Rehabilitative Service and an ever-widening circle of care givers for persons with AIDS, persons with AIDS related conditions and those already having tested positive for HIV Antibodies.

This Network operates with a complex combination of federal, state and private money. Similar, but smaller treatment networks are under development in Broward and Monroe Counties - as well as in West Palm Beach. The goal, of course, is to link all of southeast Florida with a sophisticated and accessible care and treatment system that is in a position to provide humane and appropriate services regardless of the stage of infection or ability to pay.

Still missing, but services for which new funds are being used, are residential programs for adults and children, programs specializing in care of addicts (IV and other drugs) with AIDS, and programs addressing the interface of mental health and AIDS care.

As part of this implementation process the South Florida AIDS Advisory Committee was formed and funded in part by the Robert Wood Johnson Foundation and the Health Resources and Services Administration of the US Government.

The Committee was organized by the Health Council of South Florida to effectively mobilize and coordinate the whole community to address and resolve the non-treatment issues surrounding AIDS, as well as to provide advice and coordinate assistance to Dade, Broward and Monroe Counties care and treatment networks. There are currently 37 members on the committee from the tri-county area that has a population of approximately 3 million.

As part of its advisory function the Committee is very active and has itself adopted the following goals.

- Continue the community dialogue around Aids begun by the Ad Hoc Committee during the planning process;
- Undertake additional AIDS related plans and projects that may be required in the future, including annual review and update of the current plan;
- Encourage and nurture Plan related implementation efforts taken by other community agencies and organizations;
- Fulfill a leadership role in continuing efforts toward a community-wide approach to AIDS information and education;
- Serve as the community-wide advisory board to the Public Health Trust and its subcontracted agencies as required for receipt of foundation funds; and

- Provide requested advice and information regarding AIDS and related issues to all South Florida residents.

To this end, as planning is an ongoing process the committee will continue to update as well as add additional chapters to the current plan within the next couple of years. This committee is also talking about the best way to include Palm Beach County with the development of an even broader regional AIDS plan for South Florida. Part of this effort has taken place through an informal Consortium for AIDS Related Education Services (CARES) and its efforts to implement the public information and education chapter of the original Plan. And, in the past 6 months, the Statewide Health Council (a consortium of Florida's eleven local health planning councils like the HCSF) has published an extensive policy report addressing AIDS in the public schools.

Finally, the opportunity to address distinguished members of Congress would be wasted if we did not point out the Health Council of South Florida's concern over State and Federal legislation. This year's policy statement of the South Florida Aids Advisory Committee is attached. Please understand that South Florida seeks your leadership - not just your money. AIDS kills, and, because people are dying, the country is frightened. We must not let our fear be of other people. We must concentrate the country's anger on the virus - not its carriers. We must understand that this public health dilemma is a public policy dilemma as well. And, you - our elected leaders must lead! You must support research, accurate and honest education, humane treatment in the work place and in the health care system and those community based planners and policy makers here and around the country that are prepared to bring all of those interests together for the common good. We believe you must, we hope you will and We thank you for this chance to share these thoughts with you.

Ms. QUICK. I appreciate that. I'm more comfortable with a more informal kind of response anyway.

I also want you to know that although we are identified on this panel medical support service organizations, that I'm most proud to be sitting here with this group, that the health council is not that. The health council is the community organized leadership that you referred to in your opening statement and we have done the long-range planning earlier as is chronicled in our written testimony and in the copy of the AIDS in south Florida, a plan for action which I know that your office was among the earliest recipients of back in its completion in 1986.

I would again reiterate that this was an effort to develop a regional plan for South Florida and that now the south Florida AIDS Advisory Committee is, in fact, a three-county effort and includes people from Monroe County as well as the people you've heard from here today, from Dade County, Broward, and Palm Beach.

I think that what I'd like to do is particularly underscore some of the legal and ethical concerns that I've heard raised today because you've heard. from an illustrious group of people who are involved with care, treatment, and research, but not yet from, people who are involved with the legal, ethical dilemmas, and issues, some of which I thought I heard you asking about.

First of all I would supplement Dr. Prather's earlier comment or your question with respect to statewide policy, and I would point out that in addition to Representative Frankel's efforts at the legislature, that there is a statewide health council, which is made up of the 11 local health planning councils and it has recently published a document called "The Dilemma of AIDS, Rights of the Individual and the Health of Society." And it attempts to look at AIDS as a public health threat and the AIDS in the school system issue and volume two will be dealing with AIDS and insurance and AIDS in the work place. And I think that you'll find policies being developed in that group in which I sit that will also be helpful to you at the Federal level.

Dr. Frankel—Representative Frankel's comments with respect to the economic costs I think were important to highlight again because they are not just costs of health care. They are the days of work lost, the houses foreclosed, the cars repossessed. We are talking about a monumental impact on our Nation's economy and although I share your concern about where the money will come from, I'm equally concerned about the productive money that's lost.

I think that Dr. Fischl's comment with respect to the need for additional training for health care workers is an important one to bring out and reemphasize because I'm concerned that the only way to get community physicians like Dr. Droller and others to participate, as well as nurses from the Veterans Administration and social workers from the family health services, will be to participate in training programs that help them alleviate some of their fears and understand better how they can be participants. It is inappropriate for us to be developing a separate and nonequal health care system. We need to have AIDS care

within the system of health care that we have. And clearly, as Dr. Howell said, one way to do that is to invite to the table for future planning and coordination all of the area's health care providers.

Yesterday, Senator, I was at the Southeastern Association of Health Planning and Development Organizations and heard from people from Tennessee and North Carolina and Georgia to discuss where they are with AIDS. I have to tell you where they are today is where we were 3 years ago. And I think that your Senate's efforts to do something now will be particularly helpful to those who have not yet sat at the table and discussed this issue.

I also wanted to point out that if Dr. Scott is successful in care and treatment of children and they live longer, that we will have additional issues to deal with with AIDS in the schools, not just what do we teach our children but how do we accept those who have the virus, how do we provide special education for those who have suffered the effects. Those issues will be exacerbated by her success.

Dr. Eisdorfer's discussion of desperation and depression, I have to reiterate it was because of society's response to these people. If we have accepted them as, in fact, ill people, OK, in a humane way, then perhaps some of that desperation wouldn't be there.

I have in my possession letters that indicate and documents from insurance companies that talk about discriminating against people based on their lifestyle, Senator. Not based on having AIDS. Not a discussion of charging them a higher premium because of the higher health care needs, but, in fact, not accepting them at all, OK, because of where they live and how they were.

Finally, I would reiterate and support Dr. Parks' discussion about shared resources in the research area. But I would not want to do that without suggesting to you that what we really need is a three-pronged approach to resource allocation, one for care and treatment, one for research and perhaps even research space, and one for education. And not just education for those at risk to prevent AIDS and talking about condoms on television, but education with respect to the fact that people are people and that to end some of the fear and discrimination by having a more educated population.

Finally, I want to point out that the self-help groups and the original volunteers are certainly well represented here by Ms. Dodd, Mr. Parks, and Father Tondalo. They're some of the best people that our country has to offer and they're excellent examples of the kinds of creative problem solving that the health care system has made out of this terrible crisis and dilemma.

And finally, I guess I want to go back to my original prepared testimony to say to you that the opportunity to address even one distinguished Member of Congress would be wasted if we did not point out the Health Council of South Florida's concern over State and Federal legislation. This year's policy statement of the South Florida AIDS Advisory Committee was attached to my original prepared testimony. Please understand that south Florida seeks your leadership, not just

your money. People talk a lot today about the need for money. But what we really need. Senator, is leadership.

AIDS kills. Because people are dying the country is frightened. We must not let our fear be of other people. However, we must concentrate our anger on the virus, not on the carriers.

We must understand that this public health dilemma is a public policy dilemma as well. And you, our elected leaders, must lead. You must support research and research space and accurate and honest education, humane treatment in the work place and in the health care system. And those community-based leaders and policymakers here and around the country that are prepared to bring all of these interests together for the common good. We believe you must, we hope you will and we thank you for this chance to share our thoughts with you.

Senator CHILES. Thank you very much.

How widespread is the preemployment testing for AIDS in Florida?

Ms. QUICK. I think the testing for employment is not particularly at this point widespread. Testing for insurance purposes is itself not also widespread. However, I have documents from insurance companies that would indicate that they are, rather than testing, discriminating against people based on what they call models of lifestyle. And I could read to you, for example, from a letter I had from an insurance company——

Senator CHILES. Well, if you would just submit that——

Ms. QUICK. I'll be glad to.

It says that you shouldn't hire people or cover people who have jobs that don't require a lot of physical exertion such as antique dealers and florists, OK? So I think that we're talking about discrimination in advance of testing, not just testing in order to discriminate.

Ms. DODD. Senator?

Senator CHILES. Thank you.

Ms. DODD. May I also add to some of your questions about testing and counseling and to say that in the past 2½ months at health crisis networks we've had seven callers who called on our hotline who had received notice of their HIV positivity after being tested at such reputable sites as the Dade County Health Department's alternate test site programs and through the American Red Cross and all seven of those people had committed suicide between the time that they called and the time that they were scheduled to see a counselor. For one woman that was a call at 2.30 in the afternoon before her scheduled appointment, at 7.30 she had killed herself.

As a result, at HCN we have now instituted policies whereby all callers and clients who learned of their HIV positivity are treated as high risk for suicide. I think that these kinds of anecdotal statements can only underscore the importance of an adequate testing and counseling program wherein pretest counseling is a very thorough and oftentime consuming process where good informed consent is received from the person who is being tested.

Senator CHILES. The figures you gave are terribly alarming. Was that seven out of seven or was that seven calls and then you had many more

which you did counsel? I'm just trying to get my mind, even seven is a huge number.

Ms. DODD. We had about 35 in that 2½ month period who had called saying that they needed some followup counseling even after they had received some counseling when they got their test results and of those seven killed themselves.

Senator CHILES. Of that 35, 7, that's still a——

Do you know whether, do you know when someone is given that result, is there any immediate counseling that's given at that time or is it they're just given the test?

Ms. DODD. No; indeed before the test generally there is preliminary counseling that may take 30 or 40 minutes and after the test there is, there is an equal amount of time given to telling the person how to avoid additional transmission or reexposure.

What we've learned in our educational approach is that it takes a long time, repeated information, and good peer support for people to actually change their behavior, No. 1, and No. 2, that because we're seeing now possibly as many as 90 percent of the people who are infected ultimately going on to develop full-blown disease, that in effect we're delivering a death sentence when we deliver news of HIV positivity.

Senator CHILES. Mr. Max, your Center One budget is largely from private funds and you're supported by volunteers. Do you think that volunteerism will work in areas where the AIDS victim or the IV drug users or prostitutes——

Mr. MAX. Yes, I do; because I have noticed even in Broward County, where we don't reflect those but we have volunteers from all segments of the society to deal with any one and any situation that a person might be in that happens to be affected by AIDS. We have seen very little in the sense of discriminatory, not on response from the community, when it comes to responding to people's needs. The majority of our cases are homosexual men and we have everything from, from 73-year old Jewish grandmothers to teenagers willing to volunteer their time and to help out. It really doesn't seem to make a difference when an individual has the heart to do something for another human being.

Senator CHILES. Mr. Max, what's been your experience in Belle Glade with the treatment of patients out there? Are volunteers available out there in support?

Mr. MAX. It's very difficult because people are concerned in the Glades about earning a living and it's very hard to mobilize volunteers. We have a nice relationship with the—you did mention Haitians—was it the Haitian community in specific?

We have gotten a lot of press because we made overtures to the Haitian witch doctor and we've done everything to talk with various people as we do to any unique—you know, when you—to any unique ethnic group.

We work very closely with the Haitian Catholic Center there but as I said the difficulty with working with Haitian persons is that the entire

attitude toward the disease is something of a curse. And because in AIDS you can get better it's as though the curse has been resolved. So it takes—but then I think this points up for example, just in Belle Glade, which is a mosaic of many different cultures, that the education, the work with people has to be very grassroots and related to the cultural and ethnic differences of every population.

Senator CHILES. I'd like to ask you if you all could tell me, do you feel there are enough confidentiality protections in place so that people will come forward for voluntary. counseling testing?

Father TONDALO. I think in Florida, I think there is. At this point in time, with the anonymous test sites that are available and the commitment by the State to remain that way at this point in time.

What I think has been a real big problem, however, with the blood service, in informing individuals of their HIV positivity, it's done by letter, done by registered letter. The letter is not restricted to one individual. It's simply sent to the home which means that anyone could theoretically open the letter plus the fact that there is no immediate counseling available for that individual to intercept the kind of behavior that Ms. Dodd was talking about. So, I think we need to reevaluate the way that we tell people about again, reiterating what Ms. Dodd had to say, and also perhaps putting some restrictions on that type of information given to individuals that test positive through blood centers especially.

Ms. QUICK. Senator, one of the concerns that the State health council is looking at is that even when you have alternate test sites, if people are allowed to ask if you have ever been tested and to somehow or other use that as a proxy for some expectation that you are at risk when it comes to employment or insurance or even life insurance, not just health insurance. Then the, you know, it serves as a disincentive to go to an alternate test site even though you know that once there they will treat the information confidentially. Frankly, we need some protection of law that those questions cannot be used as proxy measures of lifestyle and I think that, in fact, as we think about the more and more places where people's blood is being tested, because it is, in fact, their blood, not them that's being tested, applications to participate in the military, having your blood donated at your work site for the Red Cross, there's a lot of places where your blood is going to have been tested. And to ask that question and use it somehow for discrimination on employment, insurance, bank loans, you know, anything like that will discourage people from voluntarily going.

Mr. MAX. We will have still another dimension to the problem too as alluded to earlier in which we have many people here on illegal status and they, of course, will not come forward for any testing program. This is why we're very careful, particularly in the western county to have professionals who are of that county and I think just now we're starting to see that community coming forward, trust developed, but this is a long and hard process.

Ms. DODD. Finally, I think that one of the things that was not stated is that we're seeing an increase in unregulated testing sites. We under-

stand that K Mart at one point had wanted to put a testing facility in their stores. We're understanding there are private physicians who will offer a card that says that you are antibody negative or antibody positive that I guess you can show to people that you would like to have that information. Certainly private laboratories and research facilities, pharmaceutical companies are beginning to entertain the notion of certainly for profit testing on a large-scale basis.

Senator CHILES. Well, again, that points out how complex the whole issue is and how we come forth.

I want to thank each of you for your testimony and tell you that I may have a few questions I'd like to submit to you all in writing. The time just doesn't seem to be long enough to get into this.

And Ms. Quick, you were very kind in your remarks and let me tell you, before you can leave, you've got to understand something and so I'm in the process of trying to see if I can get some kind of a grasp and I'll have to tell you right now that it is kind of overwhelming to me and I recognize the extent of the problem that we have here. And I think there is more recognition in the country and certainly the Congress, but it's one that, that is still, you know, an awful lot of information and knowledge that we have to learn and we have to sort out as we try to make some of these judgments. Thank you very, very much for your testimony here today.

And once again I want to thank everybody that appeared here today. You're certainly all doing outstanding and important work. We're going to try to understand the information and lessons that you've related to us today in trying to develop Federal policies and budgets.

ADDITIONAL SUBMITTED MATERIAL

At this point in the record I will insert a letter from myself and information from Mr. Robert Kunst, director, Cure AIDS Now in the record.

[The information follows:]

LETTER FROM SENATOR LAWTON CHILES

September 10, 1987

Mr. Robert Kunst, Director
Cure AIDS Now
2240 S. Dixie Highway
Coconut Grove, Florida 33133

Dear Mr. Kunst:

Thank you for your recent letter and the material which you enclosed concerning your organization's efforts to help the victims of AIDS.

I appreciate your letting me know about all you are undertaking and will be pleased to include the material you submitted in our hearing record. I expect that the hearing will be printed by the end of the year.

With best wishes.

Sincerely,

Lawton Chiles

Lawton Chiles, Chairman
Labor-HHS-Education Appropriations Subcommittee

LETTER FROM ROBERT KUNST, DIRECTOR, CURE AIDS NOW

August 20, 1987

Senator Lawton Chiles
Russell Senate Office Bldg.
Room SR 250
Washington, D.C. 20510

Dear Senator Chiles,

After seeing the news report on Televison regarding the hearing you held in West Palm Beach I must say that we at Cure Aids Now, Inc. were both insulted for not being invited but irate at the politics going on between the different organizations in holding back the entire effort on this AIDS Emergency and the cover ups that we all will pay for on many levels in the near future.

After traveling around the world acquiring information on the AIDS Crisis internationally, lobbying for world-wide research funding and establishing ourselves with news media on a global level we now have our International Center. Our "MEALS ON WHEELS" programs is the first in the nation sponsored

by local government. (CITY OF MIAMI AND DADE COUNTY) Our agenda is to establish a nursing facility, emergency shelter, confidential testing center with pre and post test counseling, a dental clinic and communal, social and support groups for PLWA's and their loved ones.

We are in the process of establishing a vast outreach program into the Black, Hispanic and Haitian communities as well as the total community. We have the support of community leaders who are very concerned about what is going on.

Tragically, the information that was reported at your hearing was one sided. Enclosed is a three day synopsis of some of the calls to our office, calls from people who are getting tired of the abuses and people that are dying because of lack of care, service, compassion and responsibility by agencies being paid to do a job that they are ignoring. We are taking the responsibility of doing the job without adequate funding.

We would like the enclosed information and our letter to added to the Congressional Record. We also request to appear before your Congressional Committee in Washington to explain to Congress and the American people what this crisis is all about and must be done to head off a disaster of human tragedy and financial bankruptcy.

Having done 990 interviews internationally over the last 20 months our credibility has the attention of the world press. Your response to this global emergency will be fully documented to our media contacts and the community at large.

In the enclosed New York Times story of August 9, 1987 Cure Aids Now strongly requesting that $1 Billion be spent on education and prevention annually and that $5 Billion be allocated annually for researching the immune system which will give us answers to ALL the cancers, as well as AIDS.

Awaiting your reply and committment, I am,

Sincerely,

Robert Kunst
Director

August 17 - August 19, 1987

Latin Male - AIDS Victim - taken to the hospital on Tuesday at noon....high high fever, chills, vomiting.....mother requested some water for her son because his lips were cracking and he wanted something to drink.....nurse refused until he could see a doctor and after much insistance and the mothers part the nurse gave her two ice cubes for him...he was finally seen by the doctor at 10:00 pm and then released. The mother stated that the treatment of her son and herself was degrading and she did not wish to go back to Jackson.

Latin Male - AIDS victim - due to the deplorable conditions in which he was made to live in and the total alianation of his family and friends, were the reasons he tried to take his life. He was found by the nurse who then called the police.....The police officer was abusive...the nurse got upset....the reason given by the police department for the abuse was that HRS gave a talk to the police department and scared them into panic... Patient was taken to Jackson Memorial where he stayed in the emergency room for over 48 hours before being admitted. The did try to discharge him due to lack of bed space.

Haitian Male- AIDS victim-living in deplorable conditions, cannot feed himself and has no facilities to cook the food that is delivered.

Haitian Male- AIDS victim- in and out of Jackson....constantly discharged due to the lack of bedspace.....back to the deplorable living conditions without supervision.....seen by visiting nurse.

Latin Male - IADS victim - calls us for help....had been vomiting and had diarrhea all night long.....had no strength to get out of bed and cook himself something to eat.....three phone calls by CAN finally got someone to take care of him.....no one knew whose patient he was.

Latin Male - AIDS victim - County Health Dept called to get him on our meals program and other services.....not hospitalized at Jackson.... IMC patient.....South Florida Aids Network could not handle this case.....Finally got Visiting Nurses to look into the case. We have been working with Visiting Nurses for approximately 4 months and they did not know who we were. Social Services at Cedars Hospital came to the rescue of this elderly gentleman.

NARRATIVE REQUEST FOR PROPOSAL IDENTIFYING NEED AND OUTREACH/MONTHLY SCHEDULE

Our community based, highly sensitive, and culturally integrated approach to the 'global' AIDS menace, has made us one of the most effective and successful non-profit agencies anywhere dealing with this issue.

Since 1985, we have been enormously visible with the truth about AIDS, that even though locally based, we have had over 900 media interviews from around the world in the last 20 months. This extraordinary impact in reaching millions has also been a boon in public trust and credibility that allows our outreach to be so highly maximized and effective.

When the press wants commentary on the daily AIDS 'issues' they come to us and we have enormous clout in reaching so many more people to hear our messages, educate themselves on prevention, and to channel frustrations into positive changes that all benefit from.

We have reached out to all gay, bisexual, heterosexual 'sexual' and non-sexual people, monogamous and non-monogamous and within the total Anglo, Black, Hispanic, Haitian, and Caribbean communities of all ages, preferences and affiliations.

In other words for three years, we've made AIDS everyone's issue, <u>all</u> are at risk of getting, living in fear of getting, and/or paying for someone else getting.

Miami/Dade County is truely unique in this regard for we have the highest heterosexual spread in America that is 42-45% or ten times the national 4%.

Our Black cases are 44% compared to a national 25%. Our Hispanic cases are 24% to a national 14%. We have more babies than anyone outside of NYC. And we have only 13% 'heterosexual IV drug use' compared to a national 17%, in spite of our reputation of being the drug capital of the planet. Why are we so different?

Of course we also have a huge Haitian population and there are now many from the Caribbean, Latin,and Central America also coming here for treatment and answers.

Yet in spite of the too little, too late approach 'politically' that has held back any real serious education amongst minorities, we have enjoyed a considerable impact with the total community and the credibility for the last ten years since leading the opposition to Anita Bryant and her anti-gay 'witchhunt', which has made Miami the most talked about sexual community in history and all of it non-violently.

Such confidence and rapport is essential in reaching minorities that is our expertise and which the Health and Rehabilitation Services AIDS Division has already included our participation in a forthcoming grant to educate and prevent the spread of AIDS within the Black, Hispanic and Haitian communities, because of our track record.

We are getting part of the $7,000,000 for Minority education provided by the Centers for Disease Control in Atlanta.

Right now there are 1100+ AIDS cases in Dade County and ten times that figure for 'pre-AIDS' and ½ million people carrying the virus. Dade County has ½ the State of Florida's cases, and all of this is doubling annually and at Jackson Memorial Hospital, every nine months.

Our problems are acute, the funding minimal and therefore the needs we desperately have and are asking for in recognizing that the future horror of total community spread is already happening here and the tidal wave is only beginning.

We are the only agency to submit a grant proposal for a 24 bed residency operation in Dade County, where nothing presently exists and we are awaiting word on this critical issue as well.

In the meantime, for the last 6 months, CURE AIDS NOW has embarked on a 'role-model' "MEALS-ON-WHEELS" program for People Living With AIDS. We have put over 3500 meals into people's homes plus a buddy system that has made an enormous difference in people wanting to stay alive, put weight on, feel wanted and not abandoned and given us an education of just how bad things are and are getting.

Presently uder the supervision of Marlene Arribas, our Director of Operations, and begun by myself with a volunteer force of 17 people, we have the only program in the United States with public monies going into buying our food, we deliver.

Even San Francisco has been given 2 vans for deliveries but no monies for purchase of foods. The City of Miami, at our insistance and expertise and placed $20,000 to be committed for feeding People Living With AIDS that has been matched by Dade County.

At the recent AIDS and Minorities Conference in Atlanta, August 8-9, 1987, our efforts in this area were a tremendous hit for the 1000 delegates attending. We also got tremendous national coverage as to having $1billion for education and $5 billions for researching the CURE that got CNN, A.P., The New York Times, The National Black Radio Network, and other Black tv media to focus on our expertise within the communities.

We have 60% of our clients Hispanic and 35% black, that we are presently feeding.

But doing this outreach and service has also given our outreach tremendous impact and trust, recently witnessed on August 2, 1987 at the Jamaican Festival where our 7 volunteers leafleted the many thousands (who came to party) about AIDS and Prevention as also handing out the Surgeon General's Report on AIDS and our local leaflets. The response was terrific amongst all participants and we took one more opportunity to get everyone to realize what is at stake if anyone ignores what is going on here, let alone the future if we are going to have one. Rep. Dante Fascell got us 10,000 S.G.Reports

Our only limitations is funding resources to enhance what we are already doing without those resources, but could greatly expand upon with those resources.

Recognizing that people in all groups are sexually active, our "Counter AIDS" Condom has made quite a hit from addressing classes at Miami-Dade Community College to giving them out at the Unitarian Church.

We wish to greatly expand this effort with prostitutes, where 42% of them are now testing 'positive,' in Dade County and greatly make up all minorities.

We are reaching out to all drug treatment centers for volunteers to work with us in this critical area of prevention.

Public speaking in all schools, youth groups, police athletic leagues, business and professional groups, are all part of our outreach to include churches, in minority communities.

I am scheduled to speak before the Plumbers Union #519 on Aug. 25, and do a show on WEDR, which is the key black radio station on Aug. 27. Just taped an hour for Y-100 on Sunday the 16th another teenage to adult listening rock station.

This 12th of August the Hialeah Police Department let us know of their interest in our AIDS Training program for Police nad Prison officials.

So with all of this already in motion, we are negotiating with a Spanish radio station to do an education program at our headquarters which is blatanly on the corner of one of the most heavily travelled streets in Miami with about 100,000 cars passing, daily and Metrorail trains, all visible to our Center and message of outreach and need.

Now to get our volunteers with tables at flea markets, at the fairs and malls, and at the key festivals from the Bahamian Goombay which draws ½million to Calle Ocho which gets 1 ½ million, to the Coconut Grove Arts Festival with 1 million and so many others that brings so many out to party and to enjoy community.

We have a record we are producing about AIDS donated to us by a legally blind woman that we can do in 'rap', salsa, and other forms of music to reach everyone.

We want to do a comic book about AIDS, show films, especially what is already working in Puerto Rico, and these are just a few of our efforts with a volunteer force that is made up of all the ethic minorities we've reached out to, to get to volunteer, to practice safer sex, to help prevent spread, and use of dirty shared needles, and to help all to feel personally responsible in not adding to the crisis, personally & socially.

We are not duplicating any existing efforts but uniquely doing the most with the least amount of financial resources. But we do get high mileage for every penny spent and expent to be the #1 role-model effort in the nation that is the most cost effective as well.

We've rapped to junkies and street kids in the black and hispanic communities and won their confidence. Their concern and also their despair about anything making a difference was also a major education to ourselves, to which we responded that the only losers are those who give up and that taking back control over one's life could be made and we'd gladly help to overcome this self and socially destructive behavior.

AIDS, dramatically illustrates the bankruptcy of the total health care system and delivery of services let alone education, so efforts from other communities that have worked we too are applying as well as sharing with others our successes.

We hit the bars, the clubs, the hangouts for all at risk. Our high visibility on all levels is an invitation to communicate, especially because we are also critical of those wasting prescious time and resources none of us has the luxury to do, and shows our 'emergency' and 'emotional' appeal that builds the trust for such dialogue.

If after all that has been said about AIDS can only get 4% of the white population to change behavior, according to CDC, than perhaps the other efforts aren't worth repeating.

We believe that Black, Hispanic and the community at large have a higher percentage of behavior awareness than the rest of the nation due to our efforts combined with all that has been said as well.

We also believe that making the parents feel comfortable about talking about sex and non-needle sharing will help to educate many youngsters who are at risk, to be complimented with our direct street appeals, media appeals, program appeals, school appeals, and special events appeals.

We invite feedback and document all incoming calls, volunteers, hours, and loving letters and donations that has made our loving efforts a reality. We wish to expand this as well through audio and video taping sessions of such community based outreaches, that will be ongoing because of our compassion and dedication to overcoming this horror.

On May 4, 1987, we got the only and first comment from the National Conference of Black Mayors on resolutions regarding AIDS.

We are wanting to do programs in housing projects, and have commitments for training the staff of the Family Planning Center in Liberty City. We are also in touch with over 150 agencies from hospitals to clinics, to the school board to religious institution about public speaking and our total program.

Because CURE AIDS NOW is also embarking on a clearinghouse information as well as 'testing' (confidential) and counseling, a dentistry program, communal socials and dinners for People and Family Living With AIDS, and a host other new and exciting programs we can invite the total community to participate in our Center and/or their place of, this too will be a reason for involvement and concern.

Our location is at the heart of Little Havana, Coconut Grove, Coral Gables, Brickell Avenue, Kendall, Key Biscayne...in other words only a couple minutes from I-95 and easy access to a huge community we are already servicing with our Meals on Wheels program.

Two of our staff speak Spanish. One has a background in staff management, and one catered to rehabilitate prisoners after leaving jail, have the compassion necessary to deal with such an overwhelming situation, and talent to match in leading so many of our volunteers who also fall into so many of the minority communities we are making so much headway with. Two of our black volunteers are women in nursing, writing and funeral business. Two other black male volunteers are business professionals, and two others are street people. We have 8 hispanic volunteers so far, and more calling daily.

We are also networking with five members of the Haitian community, and also a number of gay and bisexual and heterosexual professionals. We also have four testing positive volunteers and six actually with AIDS who are able to come in regularly, and daily more people of every background volunteer to help or donate something to the operation.

The enclosed are only brief examples of our vast impact we are making a difference with that deserves your attention and support.

Understanding the many schools of thought regarding sexuality and drug abuse, range from:"Is it worth dying for?" to "Is is worth living without?" Recognizing this reality gives us the edge.

There are many willing to be celebate. Many who will practice safer sex. Many who already feel 'contaminated.' Many who are going to party no matter what.

We have explored the difference between oral and anal and vaginal sexuality, and no one has objected from any outreach we've made from the Rotary to the National Council of Jewish Women to Hispanic television to Black radio, etc.

The truth opens many doors.

We've put out 10,000 "Cure AIDS Now" Bumper Stickers and over 5000 buttons. We're about to do tee-shirts as well.

We are now adding : "STOP AIDS NOW" AND "I LOVE PWAS" stickers as well.

We have also redefined AIDS as "ALWAYS IN DIVINE SPIRIT" and the courage of those showing us the way is inspirational and catching, while AIDS itself isn't casually transmitted.

Our Center is a place for those to learn how to live and make each moment count, and not a place to learn how to die.

All of this in a pasteled, tropical setting has made our attitudes and our attempts with the public quite original and appealing.

And when our attitude is different, so is the public's action and reaction to us also so very positive.

The bottom line is that we are already creating miracles that are magnificent, and with the proper funding could magnify the results grandly, that you could proudly identify with having helped in bringing about the desired results.

We hope you're impressed and will commit to our requests.

Thank you for your kind attention to this proposal.

p.s. Even Sen. Paul Simon sent us a check for $25 after reading about our Meals-On-Wheels outreach. (see enclosed letter).

Also two new developments: Now one out of every 22 men in Florida is testing 'positive' where 6 months ago it was 1 in 30 men. Also one in 75 women is testing 'positive.'

Critical news: "95% of all men in Haiti is testing 'positive' adding many difficulties to the multiple problems already in the Dade Community.

CURE AIDS NOW—THE MIAMI PROJECT

I. OVERVIEW

Winning the war against AIDS requires reaching the population through a clear, effective program of information and public affairs, medical/clinical research and treatment, testing and diagnosis, counseling and continual community outreach.

CURE AIDS NOW, INC., is creating THE MIAMI AIDS PROJECT as a Center of Operations in the heart of South Florida, in a grass roots effort to successfully implement a series of significant human services at this time of planetary crisis.

CURE AIDS NOW, INC. is Miami's comprehensive response to the state of emergency that surrounds and affects us all. For over two-and-one-half years CURE AIDS NOW has worked in the international lobbying effort with the:

- World Health Organization
- 166 Nations of the World Assembly
- The International AIDS Conferences
- National Lobbying through Congress
- State of Florida and other Action and Support Organizations.

THE MIAMI AIDS PROJECT represents a creative initiative to educate, heal, and impact each of us, and in powerful ways facilitate the necessary transformations inherent in our survival at individual and collective levels. THE PROJECT may then be seen as a model for replication in other cities.

All members of the Executive Body of CURE AIDS NOW have experience in project management. We see THE MIAMI AIDS PROJECT as a vehicle that offers sponsorship opportunities. In fact, the stated set of objectives of THE PROJECT reinforces the effective use of public affairs events, and encourages collaboration with the international, national, and local leaders and organizations through media, conventions, workshops and seminars, research, brochures, posters, survival kits, and telecommunications to bring about a heightened community awareness and involvement.

CURE AIDS NOW Inc. is a non-profit organization which funds key scientists seeking to find a cure as well as providing financial assistance to THE MIAMI AIDS PROJECT.

Working together, CURE AIDS NOW and its sponsoring organizations will create a unique opportunity to effectively reach the general populace as well as the individuals currently in need of direct care.

II. THE PROBLEM

The AIDS "EMERGENCY", out of control world-wide, is a tidal wave coming towards us. THE MIAMI AIDS PROJECT is a part of the solution, as a "ROLE MODEL" for coping with and overcoming the crisis.

As of March 24, 1987, in a poll regarding Issues Facing The Nation, the "AIDS CRISIS" rose to the number two position from number three in one weeks time and will be the number one issue for the 1988 election.

47% of the AIDS cases outside Africa are heterosexual and the World Health Organization is predicting "100 Million" AIDS infections in 5 years, doubling annually.

The present 31,000+ AIDS cases is really 1/2 the real figure, times ten for "PRE-AIDS," due to under-reporting. There are 600,000 American cases doubling annually, with multiple viruses mutating in hundreds of directions, with millions of carriers who do not know it, all within a ten year period of 'incubation.'

Florida is number 3 in the nation (People With AIDS), showing a 40% heterosexual factor. Dade County (Miami, #5) has a 45% heterosexual rate. Worldwide, outside of Africa, there is a 47% rate of heterosexual cases, in 91 countries willing to report those cases.

The first 10,000 Americans to die of AIDS cost our government $6.3 Billions in health care and lost wages. The Reagan Administration is only offering $538 Millions, mostly to patient care, not research, while pushing in Congress $1.7 Billions for "Crack/Cocaine" that will see only 600 'overdoses' nationwide this year. $3.6 Billions are spent annually to reduce 'marijuana' use.

III. THE PROJECT

SCOPE

THE MIAMI AIDS PROJECT is created to effectively deal with the crisis at a local, even personal level, and reach out from there to the world community at large.

THE PROJECT intends to make use of a number of promotional campaigns to enhance public interest in its stated goals and to further encourage educational, promotional, and healing activities at the local and regional levels.

THE PROJECT's goals are:

1. To expand awareness of the dangers of AIDS and the degree to which people put their lives in jeopardy by remaining uninformed.

2. To create and sustain a coalition between business and community leaders, educators, doctors and scientists, government officials, and private individuals for the purpose of focusing community action on the many problems of AIDS, with emphasis on research for a CURE and immediate assistance to persons with AIDS.

3. To reach out in compassion to all persons affected by the AIDS crisis, without any form of discrimination whatsoever.

IV. OUTREACH ACTIVITIES

The programming and outreach activities of THE MIAMI AIDS PROJECT include the following:

- a "Meals-on-Wheels" program for Persons With AIDS
- an international clearinghouse and data research center
- adult congregate living facilities
- ongoing education and community outreach
- social services and risk management
- research laboratories
- group and individual counseling
- calendar of events

- training and educational materials
- brochures
- posters
- survival kits
- 800 (toll free) telephone lines
- quarterly newsletters

Of course, sponsor identification is also part of the total scope of THE PROJECT. Sponsors' logos and credits appear on all printed and video materials. Response cards, questionnaires, and polling create opportunities for sponsors to compile a data base and/or measure public interest.

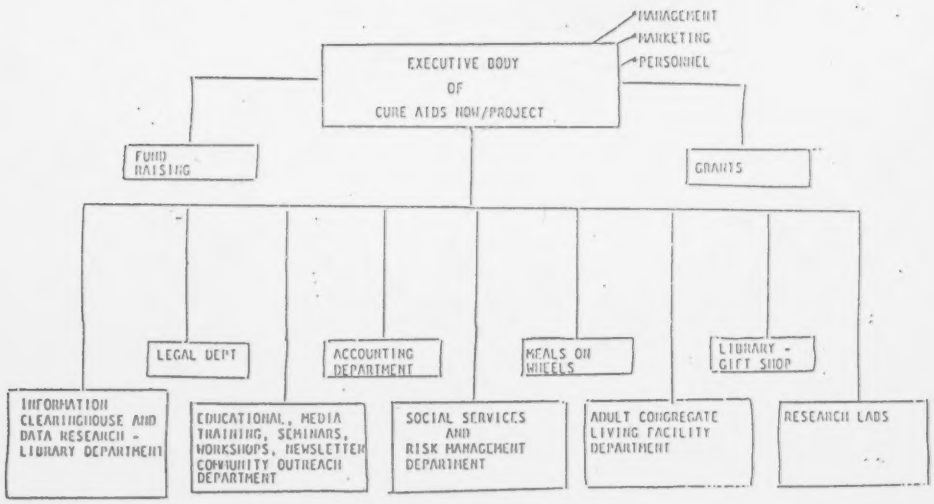
Our goal is to use THE MIAMI AIDS PROJECT as a catalyst to create task force activities and events which will unite community, religious, business, and education leaders with exemplary AIDS Prevention and Treatment Programs.

Our approach is to obtain endorsement form major international, national, and local organizations representing business and civic interests, colleges, universities, educational, athletic and health organizations, national leaders, the scientific and medical communities, and private individuals.

Representatives from higher education, pharmaceutical and chemical industries, mental health agencies, Chambers of Commerce, parent and volunteer organizations, athletic clubs, business and industry unions, churches, public education and federal, state, and local officials will be encouraged to get involved in the activities of THE PROJECT.

The staff of THE PROJECT will develop and implement plans for the effective use of local print and boradcast media, professional, voluntary and educational programs and oreganizations, brochures, posters, and presentations of THE PROJECT's activities.

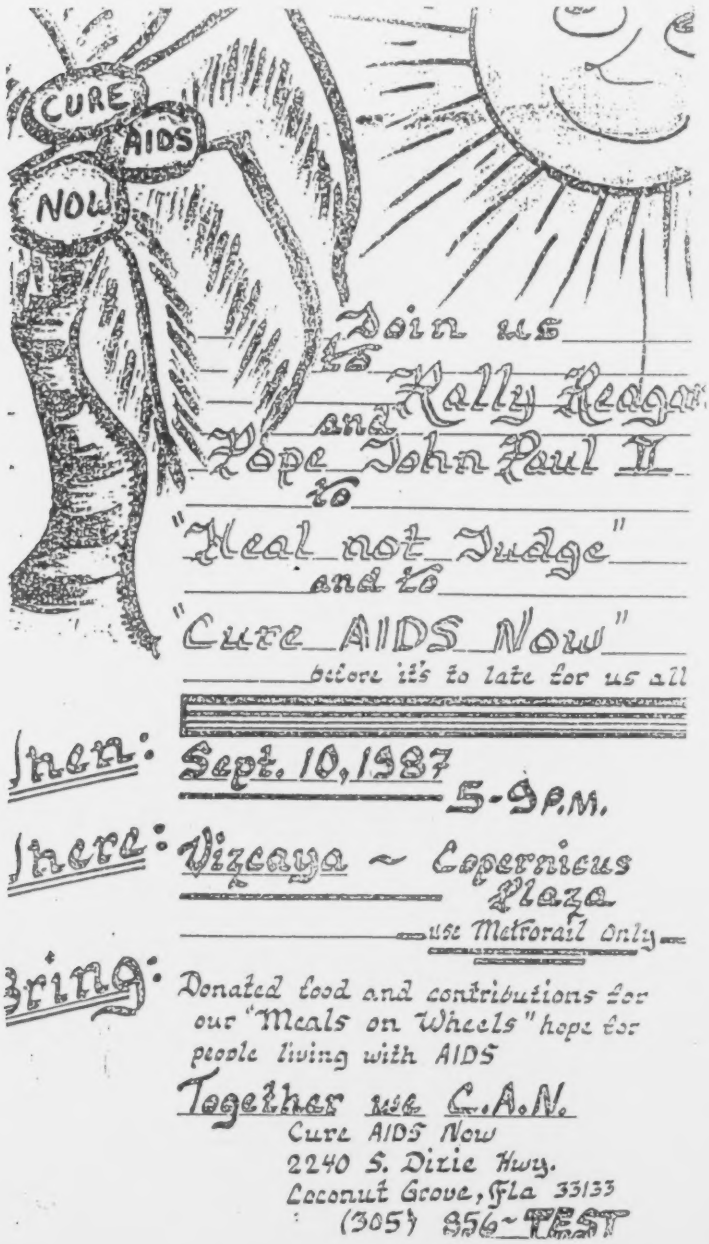
V. ORGANIZATIONAL STRUCTURE



VI. SPONSORING ORGANIZATIONS

A key to effectively conducting this Miami-World effort is the networking with other organizations which are already in place. We have met with many key organizations and will eventually contact all of them, either personally or by mail, in order to make them aware of THE MIAMI AIDS PROJECT and to gain their involvement and support.

1. The City of Miami:
Sponsoring our Meal on Wheels program



MEMORANDA FROM ROBERT P. KUNST

August 17, 1987

2240 S. Dixie Hwy., Coconut Grove, Fla. 33133 (305) 856-TEST

Dear World Media:

The next key "Harmonic Convergence" will be at this critical event of Ronald Reagan and Pope John Paul II in Miami on Sept. 10, 1987 and our very "KEY" rally to "CURE AIDS NOW" at Vizcaya from 5p.m. to 9p.m.

Why does Miami have 42-45% Heterosexual spread on AIDS? Why 44% black, 24% Hispanic, and only 13% IV to the national 17%? Why are we so different and why hasn't the media reported it?

Why has the W.H.O. focus of "100 Millions" infected in 5 years been given the credeance of a potential "AIDS ARMAGEDDON"?

We intend to make this connection at this rally, we hope you'll give coverage to.

Also is our demands from the New York Times from Aug. 9, 1987.

Also we have this "KEY" AND ONLY Letter from the Soviet Union to want INTERNATIONAL COOPERATION DENIED BY THE REAGAN ADMINISTRATION.

Also, we will send you the script of this event and we need to coordinate for maximum impact.

Thank you for your kind attention to this outreach to you.

Sincerely,

Bob Kunst

To All Persons at the
Minorities & AIDS Conference
Sponsored by the C.D.C. in
Atlanta, Ga...Aug.8,9 1987

In the last 20 months, we have established ourselves as International Authorities & seekers of research funding in over 900 media interviews worldwide. We have also delivered over 3500 meals in Dade County for People Living With AIDS. This is a 1st in the nation "Meals On Wheels" program sponsored by the City of Miami and Dade County.

And now we have just opened our INTERNATIONAL CENTER AND HEADQUARTERS at:

2240 South Dixie Highway, Coconut Grove, Florida 33133
(305) 856-TEST.

We are doing a vast outreach into the Black, Hispanic and Haitian communities as well as the total community via media, leafleting, public speaking, training and a host of programs from youth groups to the churches we are now developing.

Dade County has the highest percentage of heterosexual spread for a major city outside of Africa. And 44%-45% of our case are Black non-Hispanic, to a national 25%. Hispanic is 24% to the national 14%. And even though we have the reputation of being the 'drug capitol' of the planet, we have less IV Heterosexual spread (13%) to the national 17%. Why? Why are we so different? And as a result of our efforts to identify our demographics vs. national and to incorporate an international approach, have we made a dent in trust where the whole community feels at risk, wants the truth about prevention and our CURE AIDS NOW efforts?

Our 'role model' programs offer Communal, Social and Support groups for People Living With AIDS. In fact we've redefined AIDS to mean: "ALWAYS IN DIVINE SPIRIT." We are inspired by the courage and will to make each moment count and to regain control over one's life.

We also offer counseling before and after testing, and we're aiming to establish a nursing-care facility for 18 adults and 6 children. Also a dental clinic, and have already a training program for police, fire and prison employees and all organizations wanting the latest information and alternatives available.

CURE AIDS NOW is establishing an International Clearinghouse to find out what is going on with whom, and we ask you to submit from your agency anything from materials to news stories you feel would be relevant to be passed on, as well as receiving collated data.

We are also going to be leading a massive rally and DANCE FOR LIFE on Sept. 10,1987, when President Reagan and Pope John Paul II meet in Miami. Our message is: "TOGETHER WE C.A.N.(CURE AIDS NOW)." "War on AIDS not Sex", and "Get "POLITICS" out of this Global Medical Emergency." We are calling for a "Manhattan Project" ON AIDS with round the clock research of the 'immune system' that will give us answers to all cancers and leukemias besides AIDS.

With 6 viruses and HIV with over 1000 mutations, a 15 year 'incubation' period and predictions from World Health Organization of "100 Millions" infected in 5 years, doubling annually and already out of control in 122 nations willing to admit it, this potential AIDS Holocaust is real and must finally be properly addressed which is to CURE AIDS NOW, if we have any time left to do so.

Let's stay in touch and share information and strategy where everyone benefits.

Thank you for your kind attention to this outreach.

Yours Sincerely,

Robert P. Kunst

TO ALL CARING & COMPASSIONATE PEOPLE

JOIN US ON SEPT. 10, 1987

TO PROTEST PRESIDENT REAGAN'S AND POPE JOHN PAUL II's

"POLITICS" GETTING IN THE WAY OF THIS GLOBAL AIDS EMERGENCY OUT OF CONTROL IN 122 NATIONS WILLING TO ADMIT IT. THE PROBLEM IS 6 VIRUSES, WITH "HIV" HAVING OVER 1000 MUTATIONS, A 15 YEAR "INCUBATION" PERIOD AND PREDICTIONS FROM WORLD HEALTH ORGANIZATION OF "100 MILLIONS" INFECTED IN 5 YEARS AND DOUBLING ANNUALLY.

IT APPEARS THAT REAGAN & THE POPE ARE TOO BUSY HONORING THE PERPETRATORS OF THE LAST HOLOCAUST IN BITBURG AND WITH KURT WALDHEIM, WHILE WARRING ON PUBLIC SEXUALITY THAT IS IGNORING THE REAL PROBLEMS AND IN ESSENCE CREATING THE NEW AIDS HOLOCAUST BY THEIR "EXTREME INDIFFERENCE" TO THIS POTENTIAL CATASTROPHE.

THE ANSWER IS SIMPLE: AN ALL OUT WAR ON AIDS VIRUSES WITH A "MANHATTAN PROJECT" IN RESEARCHING THE "IMMUNE SYSTEM" THAT WILL GIVE ANSWERS TO ALL CANCERS & LEUKEMIAS AS WELL AS AIDS. TODAY'S PRESENT EFFORTS ARE A BANDAID APPROACH.

IT'S TIME TO WAR ON AIDS NOT STARWARS. TIME TO FUND AIDS, NOT THE CONTRAS, ETC.

AND ONLY MIAMI CAN MAKE THIS STATEMENT FOR THE WORLD PRESS TO COVER, BECAUSE WE ARE THE HOLYLAND OF GAY RIGHTS AND SEXUAL DEBATE NON-VIOLENTLY, AND ALSO BECAUSE WE HAVE THE HIGHEST HETEROSEXUAL SPREAD OUTSIDE OF AFRICA. WE ALSO HAVE 44% BLACK TO A NATIONAL 25%. Also 24% HISPANIC to a National 14%. AND IN SPITE OF OUR REPUTATION AS THE DRUG CAPITOL OF THE PLANET WE HAVE ONLY 13% HETEROSEXUAL IV TO A NATIONAL 17%.

WHAT'S GOING ON HERE? WHY ARE WE SO DIFFERENT? ISN'T THE REST OF THE PLANET GOING TO HAVE TO DEAL WITH THE FUTURE HORROR ALREADY HAPPENING HERE?

WHAT YOU CAN DO?

1. WRITE A CHECK TO US TO COVER OUR COSTS IN THIS EFFORT.
2. REPRINT AND RECYCLE AT YOUR EXPENSE TO EVERYONE YOU KNOW EVERYWHERE.
3. VOLUNTEER MEETINGS AT OUR NEW HEADQUARTERS EVERY TUESDAY 7:30 P.M. AT 2240 S. DIXIE HWY., COCONUT GROVE, FLA. 33133, (305) 856-TEST.
4. SHOW UP TO THE FOLLOWING EVENTS ON SEPT. 10 AND BRING EVERYONE.

A. Mini-Protest at 2 P.M.at St. Mary's Cathedral, NE 2nd Ave. and 75th St.
B. Mini-Protest at 4 P.M. at ARCHDIOCESE, 95th St.and BISC. BLVD.

C. HUGE RALLY TO CURE AIDS NOW . Noon to 5 P.M. preliminary street dancing. 5-7 P.M. "rally and Memorial Service".7-9 P.M. JOIN THE LIFE DANCE .

WE URGE EVERYONE TO BRING CANS OF FOOD FOR OUR "MEALS ON WHEELS" PROGRAM THAT WILL BE OVER 5000 SERVED MEALS BY THE TIME OF THIS RALLY.

WEAR "YELLOW GLOVES" IN HONOR OF WASH.D.C. POLICE WHO "POLITICIZED AIDS". MIAMI POLICE ARE WORKING CLOSELY WITH US TO SEE THAT WE HAVE A TERRIFIC RALLY.

USE METRORAIL ONLY AT VIZCAYA. THE TRAFFIC WILL BE TERRIBLE THROUGHOUT THE CITY. MAKE IT EASY ON YOURSELF AND ALL OF US.

SIGN A PETITION AT THE RALLY FOR REAGAN AND THE POPE TO JOIN US.

CONTRIBUTE MONEY TO OUR EFFORTS TO FEED PEOPLE LIVING WITH AIDS.

AND FINALLY....THIS IS A UNIQUE OPPORTUNITY TO MAKE SUCH A POSITIVE AND UNIVERSAL

STATEMENT THAT IS HISTORICAL AND NECESSARY WITH ALL THE LOVE WE CAN MUSTER....IN OVERCOMING THE USUAL BAD PRESS WE USUALLY GET AS A COMMUNITY. NOW WE CAN UNITE WITH THIS MESSAGE OF "FAITH, HOPE AND CHARITY",WITH US PRACTICING WHAT THEY PREACH.

TOGETHER WE C.A.N. (CURE AIDS NOW) & SURVIVE!

HELP US HELP YOU! PLEASE MAKE THE DIFFERENCE & WIN!

LETTER FROM G.N. KHLYABICH, VICE MINISITER, CHIEF STATE SANITARY DOCTOR OF THE U.S.S.R.

ENGLISH TRANSLATION

MR. ROBERT KUNST
"CURE AIDS NOW"
P.O. BOX 1976
MIAMI, FLORIDA 33139
USA

DEAR MR. KUNST,

YOUR LETTER TO GENERAL SECRETARY M.S. GORBACHOV, WHERE YOU SUGGESTED A COLLABORATION BETWEEN OUR COUNTRIES IN THE FIGHT AGAINST AIDS, WAS CONSIDERED WITH UNDERSTANDING BY THE HEALTH MINISTRY OF THE USSR.

ALTHOUGH THE PROBLEM OF AIDS IS NOT CRITICAL IN THE SOVIET UNION AS IT IS IN THE OTHER COUNTRIES, WE UNDERSTAND THE DANGER OF AIDS FOR EVERYBODY IN THE WORLD.

WE SUGGEST TO COOPERATE IN THE FIGHT AGAINST AIDS ON BOTH THE GOVERNMENTAL LEVEL (VIII SESSION OF SOVIET-AMERICAN COMMITTEE OF COOPERATION IN HEALTH FIELD) AND INTERNATIONAL ORGANIZATIONS LEVEL (SUCH AS WORLD ORGANIZATION OF HEALTH). THOSE PROPOSALS ARE PROBABLY WELL KNOWN TO YOU.

UNFORTUNATELY, THE SOVIET PROPOSALS DID NOT FIND THE OFFICIAL SUPPORT FROM THE AMERICAN ADMINISTRATION.

OF COURSE, WE SUPPORT THE DECISION OF OTHER COUNTRIES TO BUDGET MONEY TO FIGHT OLD AND NEW DISEASES INSTEAD OF INCREASING ARMS RACE.

WE BELIEVE IN THE VICOTRY OF COMMON SENSE AND HOPE THAT THE OFFICIAL ORGANIZATIONS AND THE SCIENTISTS OF BOTH OUR COUNTRIES WILL UNITE TO SOLVE THE MAIN PROBLEMS OF MANKIND, SUCH AS: AIDS, ENCOLOGICAL AND CARDIO-VASCULAR DISEASES, ENVIRONMENTAL PROTECTION.

SINCERELY,

G. N. KHLYABICH
VICE MINISITER
CHIEF STATE SANITARY DOCTOR OF THE USSR

Sponsored by: Mayor James Sharp, Flint, Michigan

NATIONAL CONFERENCE OF BLACK MAYORS, INC.

RESOLUTION

TITLE: SUPPORT FOR AIDS RESEARCH, EDUCATION, AND FEDERAL LEADERSHIP IN FINDING A CURE FOR AIDS

WHEREAS, the AIDS epidemic threatens to wreak havoc on this country's public health system; and

WHEREAS, the threat of AIDS endangers the health of unborn children as well as those who have been previously at risk; and

WHEREAS attempts to track the disease have raised serious questions of invasion of privacy and possible violations of individuals' civil rights;

NOW THEREFORE BE IT RESOLVED, that the National Conference of Black Mayors, Inc. (NCBM) calls upon presidential aspirants to address the issue of controlling and curing AIDS in their campaigns;

BE IT FURTHER RESOLVED, that NCBM calls upon public health authorities at the federal, state, and local levels to design testing procedures that minimize intrusion into the private lives of individuals and that respect constitutionally protected civil rights.

BE IT FURTHER RESOLVED, that NCBM deplores the racism and hypocrisy that has informed the public debate about the behavioral culpability of current AIDS victims.

BE IT FURTHER RESOLVED, that NCBM calls upon the appropriate federal agencies to streamline procedures that identify and approve new drugs for the treatment of AIDS and other diseases.

BE IT FURTHER RESOLVED, that NCBM calls for continuation of the growing effort to educate the public on methods that decrease the risk of contracting AIDS and the necessity for increasing the amount of resources needed to find and disseminate a cure.

On this 25th day of April, 1987

NATIONAL CONFERENCE OF BLACK MAYORS, INC.

Marion Barry, Jr., Mayor

_____

President

[From the Miami News, July 31, 1987]

Lifeline for AIDS victims—"Meals on wheels" helps the hungry and lonely

MICHAEL LASALANDRA
Miami News Reporter

Lorenzo's stomach had been growling all day. The refrigerator in the stuffy South Beach hotel room he calls home was empty. He didn't have a dime in his pocket. Even if he had, the 36-year-old AIDS victim was too weak to drag his emaciated frame to the corner store.

Then Marlene Arribas came through his door carrying a shopping bag overflowing with food: lasagna, fried chicken, beef stew, spaghetti and meatballs, turkey, pork chops, juice, fruit and bread.

Lorenzo, who had been waiting for the weekly "meals on wheels" visit like a child waits for Santa Claus on Christmas Eve, jumped up out of his bed, smiled broadly and thanked her over and over again.

"I've been going crazy waiting for you," he said, opening his refrigerator to show how desperate he was.

Lorenzo wasted no time in breaking open one of the seven frozen dinners and placing it on top of the hot plate by the foot of his bed.

"I wish everybody were like you," he told Arribas, as he stuffed a piece of Italian bread into his mouth.

This meals on wheels program, operated by gay activist Bob Kunst's Cure AIDS Now organization, is similar to other mobile meals programs for shut-ins except that it feeds only AIDS patients.

Lorenzo, who came to Miami during the Mariel sealift and who asked that his last name not be used, finds it a struggle just to eat each day, let alone fight off the deadly disease. In that respect, he's not much different from lots of other AIDS victims, many of whom have been abandoned by family and friends.

Jesus Sanchez, 36, who moved this week into the same Miami Beach hotel where Lorenzo lives, is one who has found himself alone with the disease he learned he had in June. "My family threw me out," he said. "They didn't want anything to do with me because I have AIDS."

James, 35, is living in another run-down Miami Beach hotel and has come to depend on the meals on wheels program to provide frozen meals and other goodies.

"I didn't have nothin' to eat," he said, as Arribas handed him an overstuffed grocery bag. "I was down to one can of corn."

James, who also asked that his last name be kept out of this story, was staying with his mother in Liberty City but moved to the Beach because: "If I'm going to die, I want to die by the water. And I don't want anyone feeling sorry for me."

Arribas, a longtime friend of Kunst's, quit her job working with prisoners recently to volunteer full-time for the meals on wheels program.

"Somebody's got to feed these people," she said. "Most of them live alone. They're on welfare and most of them don't have any money. One guy gets $350 a month, but pays $200 for rent. After he pays for electricity and telephone, he's got nothing left. He went for food stamps and was awarded $19 a month. That's cruel."

Since January, Kunst and Arribas have been running the meals program — funded jointly by the city of Miami and Dade County — out of their homes. But this week, Kunst opened a headquarters for Cure AIDS Now in Coconut Grove, near South Dixie Highway and Southwest 22nd Avenue.

For the gay activist, it's a dream come true.

In addition to running the meals on wheels program out of the center, Kunst wants to hold nightly dinners for AIDS patients, provide counseling and alternative therapies, give blood tests and serve as an international information clearing house on AIDS.

"This is not going to be a center for teaching people how to die, but for teaching them how to live," he said, as he helped unload a carload of food for distribution to the AIDS patients.

In addition to the frozen meals — which are baked by a caterer that specializes in well-balanced, low-salt meals for the elderly — the food packages include loaves of bread, juices, fruit and "whatever else we can get our hands on," said Arribas.

This week, patients got a can of nutrition supplement with their week's

supply of food. Jim Merriam, an AIDS patient and member of the North Miami Task Force on AIDS, usually obtains surplus foods and health products for pennies per item for inclusion in the food bag.

"It's like a care package," said Kunst.

Kunst obtained grants of $20,000 each from the city of Miami and Dade County to fund the meals program, but that only pays for 40 patients per week. Until now, the program has not been publicized because Kunst wasn't able to package or deliver more than that. But if the number of patients wanting the meals increases, as he expects it will, Kunst said he'll seek the funds to feed them. With the new headquarters and a growing base of delivery volunteers, he said, he'll soon be able to take on additional numbers.

"All we need is a refrigerator and a freezer," he said, pitching for donations.

"Actually, we need about a million things to get this place in shape, but I know we'll get them," Kunst added. "One guy came over yesterday and volunteered to mow the lawn. He has AIDS and it probably wasn't easy for him, but he wanted to help. We've created miracles with nothing before, and we will again."

[From the News/Sun-Sentinel, Apr. 5, 1987]

IT'S TIME FOR AN AIDS 'MANHATTAN PROJECT'

(By Robert P. Kunst)

Dear Senator Graham, our forgetful President remains detached and ineffectual. The ship of state remains leaderless. Crucial problems go unaddressed: How, for example, to prevent future messes arising from paying blackmail to terrorists and supporting dope-dealing Contras in another dirty war the Nation won't support?

There is a crisis of confidence, a stalemate, and a world image that Washington is out of control.

Yet in the capital the focus seems to be on how to save the Presidency and the legacy of Ronald Reagan—not how to save either the people or the planet.

Indeed, in his speech on AIDS last week Reagan seemed to confuse the real need for medical research with the red herring of restricted sexual behavior. The Government must stop warring on sex and start warring on AIDS.

Practicing what we preach appears to be merely a matter of temporary convenience so politicians can spend hundreds of millions of dollars trying to get elected, only to ignore what matters afterwards.

Take for example the AIDS epidemic, which is out of control in at least the 19 countries willing to admit it. Here we have the World Health Organization predicting 100 million will be infected in 5 years and doubling annually.

More than 31,000 Americans are documented as having AIDS. And due to politics, discrimination, underreporting and insurance fiddles the true figure might be twice that. Then we must multiply times 10 the number of Americans who have ARC or AIDS-related complex. Many of these 600,000 humans will require at least $150,000 in medical attention. Most will die anyway.

One recent study estimated that 2.5 million Americans had been infected by 1984 and will develop AIDS.

There is clearly a holocaust in the works.

If the Government were capable of solving large-scale problems it would recognize publicly that some forms of the AIDS virus are mutating in several directions, making a vaccine quite improbable; that millions of carriers don't know they are carriers: and that millions of people might die.

Tragically little time is left to do something about AIDS. This means that we must invest whatever it takes in a Manhattan project—a commitment on the level of our early atomic weapons research—a round-the-clock research effort to investigate the immune system and seek a cure. This could lead not only to a cure for AIDS but perhaps for many cancers as well.

Yet the President's budget asks for only $534 million, far short of the $2 billion recommended by the National Academy of Sciences.

However, Congress and President Reagan did authorize $1.7 billion to fight cocaine abuse, which so far has resulted in 600 overdoses nationally. In Broward County last year, for instance, more than 100 AIDS deaths were reported; there were 7 from crack cocaine. Clearly our priorities are befouled.

And where is the reason behind the military-industrial complex spending more than $3 billion to repair the $30 billion, B–1 bomber boondoggle? Or how about the $12 billion for the Bradley fighting vehicle that's too big, to vulnerable, and too flawed? Or the Pentagon's $35 billion black budget to prepare for world war IV—not just world war III, mind you—world war IV.

It is well, as you urged in a recent outlook article, to encourage Florida's contacts with Latin American students, better to aid the development of their homelands and counter Soviet influence in the region. But AIDS presents Floridians with a threat at least as serious as any in the hemisphere.

Here, Senator Graham, are some of the things you could do:

Recognize that the threat posed by acquired immune deficiency syndrome is far greater than that posed by Soviet missiles; push hard for an increased Federal commitment to AIDS research.

Be aware that many people are able to contribute to such an effort; bring together experts like myself who can advise you on how to cut the redtape and waste and offer suggestions on AIDS policy.

Understand that gay Americans are years ahead of the general population and have reduced their VD rate by 90 percent, that sexual preference no longer is significant when it comes to AIDS transmission; get Government out of our bedrooms once and for all and protect consenting adult relationships.

When 150,000, or 15 percent, of Florida's Democratic voters supported me—even though I only had a $6,000 campaign budget—they sent a message. You must listen to it.

[From the International Radio and Television Society News, April 1987]

It's been making headlines in print and broadcast media for quite some time, but according to Robert Kunst of Cure AIDS Now, journalists have failed to investigate the politics of this viral nightmare.

He asks, "Did you know that Congress and Reagan have allocated $1.7 billion to stop crack/cocaine, but only $538 million to research a cure for AIDS?" There were only 600 drug-related overdoses nationally this past year, compared to a total of 600,000 people who have contracted AIDS—a number which is doubling annually. Kunst points out that the 31,000 U.S. cases reported by the Centers for Disease Control, do not take unreported and pre-AIDS cases into account. The World Health Organization predicts that more than 100 million people will have the AIDS virus in 5 years, a number which will double annually. If this frightening math holds up, it means that the whole planet will be infected by the year 2000!

Kunst made the picture even grimmer by informing us that there are no blood tests available for several new viruses that may also contaminate and kill millions. And now mosquitoes in Africa have been found to carry a strain of the virus—effect unknown.

The first 10,000 Americans to die from AIDS cost our Government and taxpayers $6.3 billion in health care and lost wages, money that might have saved us from facing an AIDS holocaust if it had been put into researching the cure. But for that matter, who deserves the money for research? According to Kunst, there are just a handful of virologists who are making any difference, while others squabble, compete for grants, and play medical politics.

Perhaps the media have spent too much energy on the condom advertising controversy. This advertising seems but a modest gesture toward prevention. Has television employed investigative news reporting to the best of its ability? There are made-for-television movies dealing with the emotional trauma of AIDS victims and families, but how about a miniseries which makes a statement about the catastrophic implications of AIDS in the year 2000?

Issues seldom stay in the headlines for long. Will the media become tired of AIDS? Will journalists lose interest in a situation that seems so futile, or will they continue to battle through the bureaucracy that stands in the way of a breakthrough?

At press time, IRTS was getting ready to pose these and other questions to a newsmaker luncheon panel that would address "AIDS and the Mass Media." Dr. Art Ulene, chairman of Lifetime Medical Television and health reporter on NBC's "Today Show," would moderate a session featuring Betty Hudson of NBC, George Dessart of the CBS/broadcast group, Dr. Ruth Westheimer of Lifetime, and Francis Martin III of Chronicle Broadcasting.

[From the London Times, May 11, 1987]

SMALLPOX VACCINE 'TRIGGERED AIDS VIRUS'

(By Pearce Wright, Science Editor)

The AIDS epidemic may have been triggered by the mass vaccination campaign which eradicated smallpox.

The World Health Organization, which masterminded the 13-year campaign, is studying new scientific evidence suggesting that immunization with the smallpox vaccine *vaccinia* awakened the unsuspected, dormant human immuno defense virus infection [HIV].

Some experts fear that in obliterating one disease, another disease was transformed from a minor endemic illness of the Third World into the current pandemic.

While doctors now accept that *vaccinia* can activate other viruses, they are divided about whether it was the main catalyst to the AIDS epidemic.

But an advisor to WHO who disclosed the problem, told The Times: "I thought it was just a coincidence until we studied the latest findings about the reactions which can be caused by *vaccinia*. Now I believe the smallpox vaccine theory is the explanation to the explosion of AIDS."

Further evidence comes from the Walter Reed Army Medical Center in Washington.

While smallpox vaccine is no longer kept for public health purposes, new recruits to the American armed services are immunized as a precaution against possible biological warfare. Routine vaccination of a 19-year-old recruit was the trigger for stimulation of dormant HIV virus into AIDS.

This discovery of how people with subclinical HIV infection are at risk of rapid development of AIDS as a vaccine-induced disease was made by a medical team working with Dr. Robert Redfield at Walter Reed.

The recruit who developed AIDS after vaccination had been healthy throughout high school. He was given multiple immunizations, followed by his first smallpox vaccination.

Two and one-half weeks later he developed fever, headaches, neck stiffness, and night sweats. Three weeks later he was admitted to Walter Reed suffering from meningitis and rapidly developed further symptions of AIDS and died after responding for a short time to treatment.

There was no evidence that the recruit had been involved in any homosexual activity.

In describing their discovery in a paper published in the New England Journal of Medicine a fortnight ago, the Walter Reed team gave a warning against a plan to use modified versions of the smallpox vaccine to combat other diseases in developing countries.

Other doctors who accept the connection between the antismallpox campaign and the AIDS epidemic now see answers to questions which had baffled them. How, for instance, the AIDS organism, previously regarded by scientists as weak, slow, and vulnerable, began to behave like a type capable of creating a plague.

Many experts are reluctant to support the theory publicly because they believe it would be interpreted unfairly as criticism of WHO.

In addition, they are concerned abouts the impact on other public health campaigns with vaccines, such as against diptheria and the continued use of *vaccinia* in potenital AIDS research.

The coincidence between the antismallpox campaign and the rise of AIDS was discussed privately last year by experts at WHO. The possibility was dismissed on grounds of unsatisfactory evidence.

Advisors to the organization believed then that too much attention was being focussed on AIDS by the media. It is now felt that doubts would have risen sooner if public health authorities in Africa had more willingly reported infection statistics to WHO.

Instead, some African countries continued to ignore the existence of AIDS even after U.S. doctors alerted the world when the infection spread to the United States.

However, as epidemiologists gleaned more information about AIDS from reluctant central African countries, clues began to emerge from the new findings when examined against the wealth of detail known about smallpox as recorded in the "Final Report of the Global Commission for the Certification of Smallpox Eradication."

The smallpox vaccine theory would account for the position of each of the seven central African states which top the league table of most-affected countries; why Brazil became the most afflicted Latin American country; and how Haiti became the route for the spread of AIDS to the United States.

It also provides an explanation of how the infection was spread more evenly between males and females in Africa than in the West and why there is less sign of infection among 5- to 11-year-olds in central Africa.

Needles were reused 40 to 60 times in the vaccination campaign. Waving the needle across a flame was the main, but perhaps not totally satisfactory method, of sterilization.

Although no detailed figures are available, WHO information indicated that the AIDS league table of central Africa matches the concentration of vaccinations.

The greatest spread of HIV infection coincides with the most intense immunization programmes, with the number of people immunized being as follows: Zaire 36,878,000; Zambia 19,060,000; Tanzania 14,972,000; Uganda 11,616,000: Malawai 8,118,000; Ruanda 3,382,000; and Burundi 3,274,000.

Brazil, the only South American country covered in the eradication campaign, has the highest incidence of AIDS in that region.

About 14,000 Haitians, on United Nations secondment to central Africa, were covered in the campaign. They began to return home at a time when Haiti had become a popular playground for San Franciso homosexuals.

Dr. Robert Gello, who first identified the AIDS virus in the United States told The Times: "The link between the WHO program and the epidemic in Africa is an interesting and important hypothesis." I cannot say that it actually happened, but I have been saying for some years that the use of live vaccines such as that used for smallpox can activate a dormant infection such as HIV.

Charity and health workers are convinced that millions of new AIDS cases are about to hit southern Africa. After a meeting of 50 experts near Geneva this month it was revealed that up to 75 million, one-third of the population, could have the disease within the next 5 years.

Some organizations which have closely studied Africa, such as War on Want, believe that South Africa's black population, so far largely protected from the disease, could be most affected as migrant workers bring it into the country from the worst hit areas further north. The aparthied policy, they predict, will intensify its outbreak by confining the groups into comparatively small, highly populated towns where it will be almost impossible to contain its spread.

No blame can be attached to WHO, but if the hypothesis is correct it is a tragic situation.

AIDS was first officially reported from San Francisco in 1981 and it was about 2 years later before central African states were implicated. It is now known that these states had become a reservoir of AIDS as long ago as the late 1970's.

Although detailed figures of AIDS cases in Africa are difficult to collect, the more than 2 million carriers, and 50,000 deaths, estimated by the World Health Organization are concentrated in the countries where the smallpox immunization program was most intensive.

The 13-year eradication campaign ended in 1980, with the saving of 2 million lives a year and 15 million infections. The global saving from eradication has been put at $1,000 million a year.

[From the New York Times, Aug. 9, 1987]

DOCTORS URGE EDUCATION ON AIDS TO CURB SPREAD AMONG MINORITIES

ATLANTA, Aug. 8 (AP)—A stern education campaign aimed at black and Hispanic people is needed to curb the spread of AIDS in minority communities, which have accounted for 38 percent of the virus's victims, doctors said today at a Federal conference.

Some educators and health professionals among those attending also said they were tired of piecemeal campaigns and urged the Federal Government to commit more funds to finding a cure for the disease.

"It's the same old band-aid approach," said Robert Kunst, director of Cure AIDS in Miami. "I don't see any sense of emergency being stated here. Let's put $1 billion behind education and $5 billion behind research and stop playing games."

The conference on AIDS and minorities at the Centers for Disease Control came as the agency prepared a new $7 million campaign to educate minorities about the fatal disease. Another $3 million will be added in the next fiscal year.

RESEARCH ALSO ENCOURAGED

Dr. James O. Mason, the Centers' Director, said the education programs and support services for minorities should be greatly expanded.

But some in attendance said laboratory work should not be neglected.

"This conference is writing off the 1.5 million people who are already infected with the virus that can cause AIDS," said Bill Bahlman, of New York's AIDS Coalition to Unleash Power. "Again, they're not talking in terms of medicine and treatment."

Dramatic statistics about the incidence of acquired immune deficiency syndrome formed the background of the 2-day conference. Black and Hispanic people, 19 percent of the population, account for 38 percent of all reported cases of AIDS. Among children with AIDS, 80 percent are black or Hispanic.

According to the Centers, there are distinct racial breakdowns in the way AIDS patients get the disease: injectionable drug abuse or heterosexual transmission account for 45 percent of black cases and 39 percent of Hispanic cases, compared to just 6 percent among white AIDS patients, the vast majority of whom are homosexual or bisexual men. The disease has killed 22,747 people.

Dr. Donald Hopkins, Centers' Deputy Director who is the agency's top black official, called for tough talk in black and Hispanic communities about those groups' key risk factors for AIDS.

Eunice Diaz, director of health promotion for Los Angeles' White Memorial Hospital, lauded Federal efforts to better reach minorities, but warned that "there should not be any further discrimination and alienation against the Latino community."

Steve Sroka, a Cleveland public school teacher who has developed educational material on AIDS, said he worried that some of the emphasis on minorities might backfire.

"We have to be very sensitive not to stigmatize and discriminate," he said. "We've already got a homosexual phobia in this country, and there's going to come a minority phobia."

CONCLUSION OF HEARING

Senator CHILES. As I said, I look forward to continuing the partnership that we've developed here and I certainly welcome your continued guidance in the future and so we will recess now our hearings until further call of the Chair.

[Whereupon, at 12:10 p.m., Wednesday, August 12, the hearing was concluded, and the subcommittee was recessed, to reconvene at the call of the Chair.]

80-399 (132)